Paediatric Congenital Cardiac Services Consultation

Public Meeting 10 November 2012

Brownlow Community Hub, Craigavon

Panel members:

- Wendy Austin (Chair) (WA)
- Dr Frank Casey, Belfast Health and Social Care Trust (FC)
- Dean Sullivan, Health and Social Care Board (DS)
- Rosie Byrne, Belfast Health and Social Care Trust (RB)
- Irwyn McKibben, Heartbeat NI (IMcK)

Participant: Dean, when we were talking at the last meeting we spoke a lot really about dividing the safety and sustainability. I'm not sure if I got Miriam right or not is that not going to happen - is there any chance, I think she made a comment towards the end that there was no hope of that happening and I just wanted to clarify will it be looked at is there any chance that it can be divided, that sustainability isn't the same as the safety?

DS: It's unfortunate that you had the impression that anything wouldn't be looked at [redacted], certainly that wouldn't have been Miriam's intention. If the overwhelming view of people is that that is an issue, and certainly that's a view that's been expressed on a number of occasions, then clearly we will have to look at that. The difficulty is frankly as we have tried to explain at previous meetings – the reason why they are put together is that it needs – this isn't sustainability just in terms of that we can over the next number of years be confident of full staffing on a day by day basis, is confidence that no matter what time of the day it is, what time of the night it is, what day of the week it is, what week of the year it is that we can be confident that day in day out, hour in hour out, week in week out, that the service is exactly the same, that it is always safe. The trouble when we are running a service which is not sustainable, that is lower than the best practice that has been indicated by the standards that I've talked about, is actually that over time there becomes a risk that it is intrinsically unsafe, because it doesn't have that consistent level of safety. So that's why they are grouped together, and that was the view taken by the working group. I can assure you that we will look at that.

Participant: Because we have a safe service so it's retaining it that everybody would like more looked at, than getting rid of it.

DS: But it is important to understand, it's not enough for a service to be safe most of the time, or providing there is not this particular coming together of circumstances. It is almost to have the resilience built into the service that we can guarantee that it is safe literally every hour of any day of any week of any year.

Participant: It's just really with the whole 'Transforming Your Care' which I'm sure everybody's aware of, one of the priorities is to reduce inequality through focus on early prevention and intervention so how can this happen or be upheld if the prevention and intervention is removed from Belfast. You know, a child with an unknown condition – no intervention can happen if it's taken away and that's going completely against what our health minister has stated in Transforming Your Care.

Participant: My question is given the recent decision by the English minister of health Jeremy Hunt in relation to suspension of the review, what implications does this have for the decisions that you might now be making?

DS: As we've talked at previous public meetings, clearly I'm not taking any decision. The Minister will be taking a decision on this, on the basis of the recommendation from the working group. What has happened across the water is there was a process in place to review the continued appropriateness of the configuration of services that was in place within England. That process recommended a reduction in the number of units from 10 to seven. Subsequent to that outcome, a view was taken following challenge from at least a couple of the units that the decision to reduce from 10 to seven should be looked at again. All aspects of that decision in terms of whether seven was the right number to reduce to, and if seven was the right number to reduce to, whether they were the right seven or not. And the outcome of that process is due on 28th February next year. What is not at question though across the water is the standards that were being applied. The standards are the standards across the water, it is simply a review of how they were applied to arrive at the seven, and whether seven was the right number and if it wasn't the right number what might be the right number of units. So there is no question over the safe and sustainable standards. So it doesn't directly impact therefore on Northern Ireland.

WA: But obviously there are people there who aren't happy with it either.

Participant: Surely it is the case that they have already said that the infrastructure isn't sufficient if that reduction occurs, to actually facilitate the service in GB, never mind take on the cases from here in the North. It is my understanding that the infrastructure there are concerns that if the review goes ahead as it was originally planned in England that there isn't then the infrastructure to cope with the additional children needing treatment and care in England from Northern Ireland.

DS: Sorry [redacted], we are mixing a couple of things up here, in terms of the English position, certainly there was my understanding is there was a view that the seven units could cope with the demand from within the 10 units, but there was an implementation timeline associated with that. In terms of coping with Northern Ireland children, if that was required, we, as is known to all the members of the working group and in the public domain, have written to all the units across the water with a view to establishing whether or not they would have the capacity to provide care for children in Northern Ireland if that was the Minister's view on the way

forward and some of them have indicated that they would have, and others as you say have indicated that they wouldn't have.

FC: The safe and sustainable services review is a very controversial issue in England for two or three years and has caused a lot of difficulty between units in England. The standards as Dean said were outlined about three years ago now, but the difficulty in England is that units that considered themselves to be safe and sustainable, and indeed were in terms of their performance, the decision has gone against them, some of them to close, and the decision is a long way from being finalised in England, I think that there was an implementation group set up that outlined a 12 – 18 month timescale for decisions to take place in England. In talking to colleagues in England, the current independent review of the decision is likely to run its course in February. I think it is likely if that decision doesn't go the way some of the units want it to go, that there will be a judicial review in some of those centres or brought about by some of those centres in England. So it is very much a situation in England where things are not finalised yet, and I do honestly believe that has implications for any decision that's made here because none of the units in England actually have certainty about their own future at the moment, and I think that obviously impacts on their view of what they can express on taking on patients from Northern Ireland.

Participant: As a local MLA, I have been consulted by many parents with understandable concerns about this consultation. A couple of questions if I may. First of all can I ask the panel what guarantees can you give the parents and their views here tonight that will inform the final decision which is taken by the Minister? And then can I direct a question specifically to Irwyn – I know thousands of people across Northern Ireland have raised their concerns, and I would like to publicly pay tribute to you and the work that you have done amongst others to highlight this important issue. Do you feel that your views are being properly listened to by the department and are you comfortable with the process?

IMcK: Well, first of all, I would say yes Joanne, I would like to think and I do believe that my input and that of the Children's Heartbeat Trust on behalf of parents has been listened to. I think when we got the first piece of work about the consultation document, there was a whole lot of things that as time moved, we had our input into that obviously the medical end was left to the ones who are expert in that, but when it came to parents we were quite vociferous in what we thought that had to be included in the document. I do believe our voices were heard and I do believe that our voices were acted upon. I do believe as well that what is being said here tonight and from the other meetings by parents will be taken on board and when it does go back to the next consultation working group meetings that I'll be attending I have notes here that I'll make sure will be taken on board. And I will be fighting on that behalf.

WA: And what about the first part of Joanne's question? Dean maybe you are the person to answer that. It is a complicated process that framework idea is a difficult concept. Will the views expressed, how will the views expressed by the people who have come along to these meetings be included in this document that goes to the minister?

DS: If we wind it back a little bit in terms of one important element of ensuring the legitimacy of the process, if we call it that, is actually how the working group works. The working group is an open book that's open to any parent to come along, we've never had to turn anyone away yet and have had six, seven, eight parents at some of the meetings. That's in addition to Irwyn and Sarah, Julie who's also on the working group. So three of the working group members here in various guises tonight in terms of parent or parent representatives plus the abilities of parents or anyone else who wants to come along and observe things which I think makes it a more transparent process than certainly anything I've been involved in of this sort. That transparency will remain as we go forward and produce that document for the Minister – that will be produced in that semi sort of public environment as well, so you will all have the chance to see either through your representatives or by turning up in person as appropriate how that process works. I think the actual nuts and bolts of all of this in terms of how we take all of the input from tonight and the other public meetings, focus groups and the written response we'll have to see in terms of making that as manageable as possible. We do have a recording being made of everything tonight as there has been of the other public meetings. For each of the focus groups Parenting NI and other bodies are producing a report of the focus group and again the focus group that I was at, and I have said to Parenting NI that they can see that report in draft before it comes in to the working group – so there is a chance to comment on that. But we need to be doing more than just 'here's the answer minister, and here's a big pile of stuff we got during the consultation' so that's a bit I think that will be the challenge. It's hard to know I think until we see what it all looks like. I think the last time I looked which was Friday there were 40 or 50 responses to the consultation to date. The tougher task in a way is also distilling the likes of this evening into something. But we'll certainly aim to do that and the assurance that if I was sitting in the audience tonight and not here is that the process is as transparent as it is and that there is the ability for parents to be in the room when these things are being considered.

Participant: Just want to bring you back to the first point made there that [redacted] raised about the possible splitting of safe and sustainable or the not possible splitting of it, whatever you decide to do. You stated there Dean it's not enough just to have a safe service, it's to be safe 24 hours a day, 24/7 but for 20 years you deemed it safe to run with one surgeon. So it doesn't take a report to tell you that's not safe and it doesn't take me to stand here and say what if [redacted] got hit by a bus – what was your contingency plan there? Inactivity has totally left this service vulnerable, I made this point before as well – you are standing there and dictating about services.

It’s not enough to have a safe service even after all these years of having a service with one surgeon and possible back up surgeons from other centres and still, the Belfast centre has been deemed safe by this report in the face of all that. I do believe it’s laughable now that you turn round and say we need 4 surgeons to meet these standards – it’s got to the stage now where you can’t continue with the resources that you have put in place, and that’s why we are in the process. Also, my wife asked the question, I was actually quite disappointed that Miriam isn’t here tonight, my wife asked the question at the Belfast meeting which didn’t receive a full and direct answer. It was quite an easy answer – yes or no – the six options that have been put on the screen, the six possible outcomes which I believe is not exhaustive either – there could be different outcomes – are they there because they are safe – yes or no?

DS: Well they are there, I think it is because there is no simple yes or no answer – they are there because they are exactly what it says on the tin – possible options

Participant: But are they safe options Dean? That’s all I’m asking, are they safe? You said this before and I agree – there are elements of risk, elements of uncertainty with all the options because you haven’t fully explored them, right? And to expect to fully explore them as well for a decision that is going to affect Northern Ireland for generations to come in six months is a disgrace in itself, the whole time frame that you are rushing this through, when England can’t even come to a conclusion after two years of consultation. Are they safe or are they not safe? They do come with an element of risk, yes, but are they safe or is there a margin of error let’s say.

WA: These are the six possible outcomes for the future provision.

DS: Well I think you have answered your own question, there are elements of uncertainty, elements of risk of different types with all of the options which is why it is just not possible.

Participant: So you agree then that they are safe or they are not safe?

DS: No I’m saying there are issues with all of the options.

Participant: So they’re not safe?

DS: That’s not what I’m saying either, I’m saying.

Participant: So 90% safe?

DS: Well if we get into that we have to get into the issue of what’s the more important thing – safe and sustainable services, access to emergencies and so on – that’s why those things are there as separate criteria. It’s different elements, different criteria, that each option, you know clearly an option where the service is provided on the island of Ireland will better respond to the emergency side of things, but it may well

respond less well to other aspects of the criteria. That's why it simply isn't possible to give a straightforward.

Participant: Fair enough. That's fair enough. Again, any of them, and certainly in my mind, I'm unqualified to speak, certainly in my mind, any element there or any decision that takes surgery out of, that takes the surgical function out of Belfast is unsafe – maybe not in the short term because you can provide – yes other centres can provide safe surgery – elements of travel, but again the deskilling – my wife had asked a simple question which was responded to by a paragraph from the document which we've read so I don't want to ask again. The deskilling of the consultants in Clark Clinic – you can't say to me that a consultant who has been practicing, Dr Casey there, I don't know how long he has been there, he has practiced both the consultant side and the surgical side – you can say to me that the surgeon who comes to Belfast or sorry a consultant who comes to Belfast can only practice the non-surgical side of his job is providing a safe service in Clark Clinic.

WA: Well let's address some of those points, with the greatest of respect it's not a conversation.

Participant: Well can I have that answered? By Dr Casey

WA: Well if you give me a moment, that's just what I was going to try and do, OK? Frank, what about that element, because it is something that has come up at previous consultation meetings, about retention of dedicated and skilled staff and, just to go back a little bit to what you were saying earlier too, and this is a point that someone raised in Derry I think it was, about the fact that there had previously not been a focus on meeting future needs which is perhaps why we've ended up in the situation that we are in and I think that's a point that [redacted] referred to – the fact that this kind of plan wasn't put in place before. How do these various options play into those two particular elements?

FC: Well to look at the issue of deskilling and maintaining a highly skilled staff within the unit, well that is one of the main concerns that we have as an unwanted spin off if you like, in that removing cardiac surgery – it would be very difficult to maintain the level of consultants skilled in the future and to recruit staff who want to work – the natural tendency for people who are bright and young and enthusiastic is to migrate towards centres where there are new developments and new things happening. We believe that over the years Belfast has been a place where people have wanted to work, and it is a concern for the future. The model that's proposed in England is to have cardiology centres linked very closely to surgical centres. For us as a clinical team that's one of the attractions of looking at the model that's on an all island basis, because that gives much more scope for staff to share working sessions across the two centres.

WA: And would see there being flexibility on mobility being built in to that.

FC: Well, I think in 2012 we do have to consider that the systems that worked in the past are not suitable for the future in terms of the changing working practices of doctors, the very high tech technologies that are now involved in maintaining a whole cardiac surgical service. On the island of Ireland I think it is necessary to share skills, and we have lots of things that we can be proud of in the service in Belfast, things that we can give to other centres that we don't need to be dependent on them for, and a way of working in collaboration has to be the way forward in terms of getting round some of the issues in terms of we can't change the numbers of people in Northern Ireland. So therefore we have to treat the situation in collaboration where we can bring in skills, and that surgeons can maintain their skills by working with bigger numbers. So I think that going forward from now, that this is a very crucial time in this service, but we have to be more imaginative and change the way we go forward, and for me, in terms of making that attractive for people to work in, which is not by any means the most important thing, but to get a good service, you need good people in it, and to maintain things that are safe and develop them further we have to put a structure in place that widens the consideration outside Northern Ireland.

WA: Rosie what about the situation as regards to dedicated and skilled nursing staff? I mean at every one of these meetings, parents have paid tribute to the nursing staff for their care of their sick babies and sick children. What about those nursing staff are they going to work somewhere else if there isn't the work for them to do?

RB: I suppose it is fair to say that they share the same concerns as the clinicians in that a lot of them have been there a very long time I think Frank would agree. They have also dedicated a lot of their time to delivering a service for sick cardiac babies. But we've sort of tried to reassure them as much as we can during this process that it's been made very clear that it's the delivery of cardiology is going to continue, and it's something that we want the group to develop and add to as such. So we've sort of been very conscious of trying to reassure them.

Participant:……talk about sustainability being 400 – 500 surgeries each year, but is that not for England, like we've got such a small population compared to England, are we meant to meet those numbers?

DS: Well certainly the safe and sustainable standards are national standards that are developed from a range of professionals being involved from across the UK. But they are reflected, that element of it has certainly been reflected in the standards that are proposed for Northern Ireland, and I've explained the logic, that the view is that you can't sustain a 24/7 road without having 4 surgeons – if you have four surgeons, the minimum number of procedures that a surgeon is supposed to be doing is 100 a year. Ideally 125 a year – that's where the 4-500 comes from, it's built up that way to maintain the 24/7 – multiply by 100 to 125 to get that. But it is for consultation – it's very important that we manage to communicate that to you tonight. The view of the working group was that was an appropriate set of standards to put out for

consultation – that is what we have done. If you have a different view then we are very keen to hear that tonight or after tonight.

Participant: So if we have one surgeon can we not go ahead with 125 surgeries a year? Is that not safe and sustainable?

DS: No it's not, because you are not providing 24/7 cover is the difficulty. So that would meet the requirement of the surgeon him or herself doing the right number of procedures, in terms of having 24/7 cover whereas Frank and Rosie would be better qualified, it is very easy to think you are a one person show sort of thing, the cardiac surgeon show, but actually there is anaesthetic staff and all sorts of other staff, transfusionists and so on, all involved and nurses and so on in the delivery of care to the child. So it's about the ability of that team collectively to be doing this sort of work day in day out.

WA: Frank that is something we've heard. I just wanted to put those points that you were making to Frank, I think one of the things that people find hard to grasp at all of these meetings is the leap from a service which most people here would feel worked very well for them, to something which is four times the size and have the same effect, but sustainable, and I think we all get those points, but I think it is a bit hard to grasp that.

FC: I mean it's something that we struggle with ourselves in that we have for many years had a service that delivered this number of cases. That service did depend very heavily, and still does on a very small number of people. The first thing is I suppose to say is it's not necessarily set in stone that it has to be a leap to 400 cases – that is a standard that has been adopted in England. Most of the centres who have in fact been designated do not currently deliver 400 cases, so it's not that it is something that is already in place apart from one or two centres. The dilemma for us is in Belfast to see if there is any way that we can retain a service that continues to be safe and sustainable in the future without reaching the 400 target and one of the options that is certainly being considered is that we consider the surgical workload on the island of Ireland which is in excess of 600 cases, and that you have a team of surgeons working across two sites to fulfil the stipulations of four surgeons each doing that number of cases. The practical difficulty with that is that working across two sites is difficult, you can't provide 24/7 cover, the other side of that equation is, is that less good than having no cover for 365 days of the year? And that's the balance in all of this. So we, I would hope that in the debate that still takes place in the next two to three months, that all of those options in terms of how we consider that surgical services can be retained in Northern Ireland, if they can be retained it would have to be a different model that the past. We have to face that reality, and we have to make sure that any model that we consider would be safe as if it were delivered elsewhere. There are so many different complexities to the safety part of it, not just the operation but the whole safety of the service so, I want to assure you that we have thought, and continue to think of many different models,

and I believe at this stage that none has been excluded that's the message that we have got from the minister as well, and we will continue to debate that.

WA: Frank, thanks very much.

Participant: I just have one more question – if the surgery does happen and they are going over to England do you think it is safe for our children to fly on planes or is it acceptable for our children to fly on planes?

DS: Yes, and they do now.

Participant: Oh yes, I know – my [redacted] here went to Birmingham in [redacted] we were told [redacted] flight would be at six o'clock, then eight, then ten, and [redacted] flight went at one o'clock. Had it been an emergency situation [redacted] would have been dead.

Participant: I'm a local councillor here – you are all very welcome to our lovely facility here. A lot of the points that I want to make and ask really, most speakers have asked them, so the only things that I wanted to deal with I suppose were in terms of the whole sustainability issue. I think that all people will accept, because you have to, reality is for any service, it has to be up to a standard, it has to be fit for purpose because there's no point in having a service if it doesn't meet the needs of the people it's meant to serve, and that's just a bottom line. But having said that, meeting particular standards, it's a bit like saying 'well, a smaller country can't provide a service, or a smaller country can't meet a certain standard because there's less people who live there, because there are less people that have particular conditions.' I don't buy into that. That to me is a conservative way of thinking, in that you are not prepared to think outside the box. I'm not accusing anybody of that by the way, I'm just making my point on that. And as I said, it highlights to me that the reality of situations like this are that people have to start now thinking outside the box, and that obviously includes the politicians and the minister and all of that and, it has been mentioned about an all-island solution, or some type of all Ireland framework to make this work, and I agree with what others have said, that could be Dublin, Belfast and whatever else comes into consideration, if it improves and can provide the service. To me that is a key factor. I personally believe that it can be done and I think that the solution to this is we have to look at an all Ireland perspective, and we have to set aside all the other constitutional positions relating to that because it is only about service and you know I just want to make that point, I know people have already dealt with the specifics of it, but from my perspective that is key. If I could just finish with one other thing, in relation to a point made there about primarily being provided from Belfast and Dublin, and the comment was made that in terms of emergencies it might be able to meet those aspects, but there was a common….other aspects it would not, or might not be able to respond to. So really my question is what are they? If they are being referred to, if that's true, let us see if there is a way around them. And just finally, I haven't met Irwyn before, but I am glad to hear that he is being listened to, that his organisation is being listened to because,

again, experience and personal experience, regardless of what way this outcome goes, it's obviously going to be parents and adults who suffer and who have went through this.

WA: Thanks very much, not quite sure who would like to deal with that, Dean?

DS: I can pick up a couple of them Wendy – the first and the last one then – the reality is in terms of smaller places and their abilities to provide all of the care to meet all of the needs in a relatively small population. The reality is today, 30+ cardiac surgery procedures on children are undertaken across the water in Great Britain, let alone all the other sorts of transplants and so on. So there are already a number of procedures that can't be undertaken in a population the size of Northern Ireland. That's not to say that we aren't getting any sense that there would be a pressure in place within the system in NI, to seek to secure services from across the water for things that could be done safely and sustainably in NI, it's clearly not the case as far as possible we seek to provide the services locally as far as we can. The all Ireland question, and any political complexities if we can call it that just to assure that my sense is that both governments would be very supportive of the idea of all Ireland working but not just in this area – radiotherapy up in Derry would be another example of where substantial services would be provided on a cross border basis up there. So I think there is definitely a positive move in those regards but I don't think that would be a thing to get in the way of that. The only other point you made was around is there anything about the Belfast Dublin thing currently that would be problematic, and the only thing in that regard would be at this stage as the working group knows we have written to Dublin, at this stage it clearly would be not possible for them to respond to the planned, non-urgent cases in the sort of volumes that we are talking about there. It maybe is the case that with an appropriate lead in time they may be able to – but they couldn't do that today. They have enough challenges responding to their own demands within the south, without taking on board another 70, 80 90 cases on top of that.

Participant: Firstly I'd like to say as a mother of a child [redacted], so I'd like to say thank you very much to Dr Casey and the Clark Clinic – they were an excellent service and an excellent team. Two questions really I have, one being first of all when you were saying about the resources that were needed regarding surgeons, obviously as the health service, surely we should have planned on that two and a half years ago when the full time surgeon had retired, and we brought a surgeon out of retirement, [redacted] now, to do the surgeries and surely if we had more surgery time then we could facilitate that criteria. And also when we talked about actually reducing the numbers of surgeries which was discussed earlier because we are a smaller population why wasn't the other criteria thought about? Wasn't reduced when we talked about as I said the surgery is going to be reduced, not going to be reduced, why isn't that same criteria applied? Whenever we were talking about other standards, the criteria, the scoring hasn't reduced?

DS: Certainly in terms of the, was it foreseen that [redacted] was going to retire – yes it clearly was. I think [redacted] to be fair had stayed on long beyond when he had initially planned to retire. But as Frank has said medical careers don't work in the same way that [redacted] used to work in terms of effectively being a one man band providing surgery, that's not the model of care that's around now – I don't think there is a surgeon in the UK, sorry Frank would know better, I am not aware of a surgeon in the UK working that sort of arrangement anymore, so there's a thing of a bygone era of which [redacted] was one of the last so there have been a lot of, and the difficulty was, and there are a lot of discussions with the south as well. The difficulty was getting past the fact that NI's numbers are relatively small, so with all the.

Participant: But surely then the surgeries should have reflected that if we are taking that into consideration when we scored for surgery, then surely we should think right well then if we say we are not going to relate that to mainland England, but then now we are when we are actually going through this consultation period. And sorry there was one point, sorry in my rush to say that, the consultation period was so much shorter here, and over in England it is a period of two years. Again why did we reduce that period again when we didn't reduce the surgery numbers? Again that scoring again is not reflective of our population – if you are going to say the shorter consultation period was a result of a shorter population, well surely that surgery number you said for it to be sustainable, should have been reduced as well to reflect that?

WA: I think the consultation period was set by.

DS: Yes it's just the standard legal requirement and there are an extra couple of days in there.

Participant: Was it not two years in mainland England?

DS: Well there was as I understand it there was, and I'm not sure exactly how long the consultation period was on the safe and sustainable standards and there was an implementation timeline proposed as we were talking earlier on of 18 months to two years. I am not aware of how long the timetable was for the safe and sustainable standards. Certainly I'm satisfied that we are through the processes in time that we have, providing adequate opportunities for people in Northern Ireland to comment on the standards that are proposed. I think in terms of the specifics of the point that you are making as to Northern Ireland is smaller, why don't we drop the number of surgeries that would be appropriate certainly the view of the working group informed by best practice standards from across the water by dropping that, those standards are there across the water because the view across the water of the national bodies, and the parents who were involved in that process and so on is that's best practice service model. If you don't do 400 procedures a year in a unit, anything less than that is sub-optimal is the view, that's what we are out to consult on, if tonight we think something different then.

Participant: But if the ratio was based on the surgeons that they have, our surgeons is a lower number and surely as anybody who is a manager, you do, in a bog standard world, you do resourcing, you do planning, you do perspectives going forward of what you need – so surely when that surgeon retires.

DS: You certainly could, you could.

Participant: You should have done that.

DS: You could drop the ratio and in response to the lady when she asked earlier on tonight if it would be possible to be there or thereabouts in terms of a single surgeon doing the right number of procedures a year but that doesn't deliver for you, there is the 24/7 cover issue, and it doesn't deliver the experience of others working in the.

Participant: But as we said, that would be much better than nothing. It is a complete loss if you lose that Clark Clinic they do a fantastic job.

WA: Thanks very much indeed for those points, well made.

Participant: In terms of the numbers, from my understanding it is that in Scotland it is the same problem in regards to the numbers, and there has been an adjustment in the number of surgeries and the number of surgeons, so I don't understand why it doesn't be applied here as well.

WA: Is that the case? Frank do you know?

FC: The safe and sustainable review team did do a similar review of the Scottish surgical service which is based in Glasgow. They do just under 300 cases a year. The Scottish minister for health took the view that their service was sustainable with that number of surgeons – they took note of the comments of the safe and sustainable services team. They decided that for their population they were happy enough with the numbers as they were. I mean 300 is obviously a higher number than what we have, but the debate about numbers is one that continuously surrounds this. I think that it's probably not helpful to think of there being a magic number, there is flexibility around the numbers, and I think there will be with the centres in England, and it's trying to get something that works, that can continue without being slavishly tied to a 400 number.

Participant: My child is one of the children who had an emergency procedure and [redacted] was rushed from [redacted] to Belfast, and [redacted] heart was so erratic that [redacted]. My child wouldn't have made it to the UK. My question to you is that if my child had to go to the UK and hadn't made it, who is going to be left liable for these children who are going to die?

DS: Well as we have discussed at various forums over the last number of weeks and indeed the working group talked about this particular issue at length and there is no doubt about it, there are practical difficulties, particularly going off island in terms of

providing the emergency response within the timeline. That's not to say it can't be done, but as is made clear within the consultation document it notes the very real difficulties. If you look in the section which assesses each of the options against the criteria, when you look at the wording under the option where all surgery would be provided across the water that flags up the very real difficulties that would be around the delivery of a child's needs in those circumstances. The paper flags up that it is a small number of occasions a year, it doesn't matter that it is a small number of occasions a year, it's not once in 100 years, it is a small number of occasions every year. So we clearly have to and will be planning to ensure that a timely response is in place. And again I suppose to reassure you, we have talked about the way the working group works – any idea that we, clearly we are aware of that, that's up there as the second most important criteria and any idea that we could put forward an option that would score the highest, I don't see how – it is probably impossible that the criteria having the weighting that it has is probably impossible for an option to score highest and score poorly against that criteria. The option has to allow for timely responses in urgent and emergency cases regardless of the fact that they are relatively small proportion

Participant: Kids in the UK aren't asked to travel or fly or get in a plane – why should Northern Ireland kids be asked to get in a plane and travel to England? It's not on. We want the best for our kids, and the best for our kids is in Belfast.

Participant: Can I just ask when did the death of a child become a practical difficulty?

DS: I don't think that's what I said Dolores. No, I said there are practical difficulties with transporting a child across to England within a clinically indicated timeline – there are, the wording is quite clear within the paper.

Participant: Sorry to jump in, but [redacted] is a friend of mine, [redacted] a great child, so where does safety and sustainability come in? I think, where was it, accessibility was option four or five, but accessibility is right there at the top with safety and sustainability.

DS: It might help just to point people to the right section of the – if you look on page 24 of the document which is in the context of there being no emergency or urgent surgery being undertaken within Northern Ireland, within the island of Ireland with all surgery being undertaken across the water it says here it is not clear that this option would ensure the provision of all emergency and urgent procedures within clinically indicated timescales, under this option there will be a requirement for emergency cases to travel by air ambulance. There are a small number of children for which air travel may be a risk. The evidence for transport is that it is normally safe and effective however it is recognised if there is a clinical emergency during the flight e.g. if a resuscitation is required, this can be exceptionally challenging. The consistent availability of air transport may be impacted by severe weather and other factors. So again, to reassure people.

WA: So is that ruling it out?

DS: No it's highlighting, I suppose it comes back to the point that [redacted] was making, there's issues in different ways with all of the options which is why we have criteria and weightings and so on, because some options score better against some than others do. And as we touched on the way the working group works this issue has been talked about at huge lengths within the working group. As we've touched on in previous meetings its importance in terms of weighting increased substantially since the early draft. But again if you have a different view that we are still not getting it as a working group, even with the input from Julie and Irwyn and Sarah and others that in fact this weighting should be higher again then you have the opportunity to say that. To reassure you, and as Irwyn will confirm, there's no shortage of time that has been spent very carefully considering this as an issue, because it is a real practical issue when there is air transport involved.

WA: It is an issue that at some previous meetings has been clearly stated that people feel it didn't have enough of a weighting.

DS: That's right.

WA: Particularly if you apply it to different options for where the service may be commissioned from.

Participant: He's reading directly from the book there is elements of risk, but [redacted] child would die. My child would have died. The child will die, children will die if there is no service in Belfast and that is a fancy way, you can word it up whatever way you want in the document which takes in we are considering this element, but it is an element, children will die. It's as simple as that. You can word it whatever way you want, but that's what it is.

WA: …….this is a consultation and I'm just here to facilitate, and Dean, Frank and Rosie and Irwyn are here to answer your questions if that's what you wish. But specifically they are here to listen, you have been making your point really well tonight, it's all being written down and we've heard explanations of the way it will be used to inform the debate. Nobody's going to come up with a magic answer tonight.

Participant: Dean, something you kept mentioning there is the 24/7 cover. I'm just curious out of the six options there which actually do provide 24/7 cover if you could answer that for me?

DS: Going through them, Belfast clearly struggles to provide 24/7 cover with the staffing that we have, the other units off the top of my head, it's all set out within the document because they are scored against that, would provide 24/7 cover. I think the difficulty is [redacted] point though, which is it wouldn't be 24/7 cover within Belfast clearly with some of the options, but it would be a service that would provide 24/7 cover.

Participant: So therefore given the lack of access to the other centres, that then surely rules them out as maybe you could also answer which of the centres in the UK are within the three hour transport time?

DS: Well it's a three hour transport time in terms of the clinical team getting to wherever the child is to transport them, I haven't actually…my understanding of it would be the vast majority of them would be able to get here within three hours, but it doesn't , I'm not trying to underplay, you can't get past that big bit of water between us and GB presents real practical difficulties. I'm not trying to play down those practical difficulties. It doesn't rule any option in; it doesn't rule any option out. It just makes for an option which is solely to provide surgery across the water. There are very real practical difficulties with it providing services in the context of emergency urgent thing. We have to work it through and see what those practical difficulties feel like in practice and whether they can be overcome or not and whether even if they can be overcome, if they would still be a better option than some of the other options that are here. But it is about making sure we've got the right framework.

Participant: Sorry I have just another couple of questions – you'd said that year in year out you have these emergency situations which do require very urgent care such as [redacted] child. So does that not mean when you are taking away that access, which we do have, does that not mean that you are removing that child's human right to life as well?

DS: Well I think clearly we don't do that.

Participant: So that means that GB would be out of the options, out of the question then because you wouldn't be doing that?

DS: It would mean any option that couldn't provide access within a clinically indicated timescale for those children yes would be out of the question.

Participant: It's not just time, it's not always about time with these children. You sometimes can't send a child on a plane or air transport because of their stability, they are not as stable enough to fly. You know, we spent maybe a week to get a fit to fly home letter, after [redacted] surgery, let alone fit to fly during an emergency. Do you know what I mean? So how it's possible to say that you are not taking away a child's right to life, well how you can then include GB and removing your surgical cover from here, it baffles me.

WA: Thanks very much for your point, and you made them very well.

Participant: I just really want to first of all agree with [redacted], because again our health minister has said that it's unacceptable for the life expectancy of a child to be determined by where they are born and raised, does that include Northern Ireland? A point I want to make, the review is under review, so you are planning to go to England to look at these hospitals – why? Is that not premature? We don't know how this is going to affect those other centres in England, what is the point in a panel

going to England to look at this when they are not going to get a real fact – it's going blind. You are not going to come back with the right answers. You are not going to see the right situation. Why can that not be put on hold? Why should you go to these centres in England and not see a true reflection of the situation that they are going to be faced with? What is the point?

DS: I think it is a fair question [redacted], and one we have discussed at length before, both with yourself and with others. I think it certainly at the focus group this was discussed, one of the ones within Belfast. We talked at length about this. I'd mentioned already the fact that in January our aim is through the working group to put a paper to the Minister which is effectively the outcome of the consultation process recommending to him a framework for the decision to be made subsequent to January. But then subsequent to January we do need to be making a recommendation to the minister.

Participant: But you are not going to get an accurate recommendation.

DS: Recommendations may include in whole or part accessing surgical services at one or more centres across the water, it may or it may not. As I rehearsed with some of you before, if I was him I would expect me and the working group to have at least some understanding of where those centres are, what they look like, what it feels like on the ground, what it might feel like for parents and so on. We may not be recommending any of the centres across the water, but in the spirit of making sure.

Participant: I just think it's unfair.

DS: And I think that's a reasonable view to have. We would rather be in a place that we have seen these centres and understand what they look like.

Participant: But you are not really getting to see them.

WA: Well you've made that point if you don't mind me saying so, and you've made it well [redacted].

Participant: Firstly, on the service specification, they are not taking the child's wellbeing into consideration in the psychological, emotional and practical. When a child has surgery, they want to see familiar faces round them, they don't want to be taken away from their family and their clinicians that treat them. I know that [redacted] and it brought [redacted] round. My second point is seeing that you are going to England to see the hospitals, will you be visiting Dublin as well?

FC: Yes, Wendy can I just come back a little bit to the emergency situation? Because the dealing with the emergency or the crisis situation where the child needs urgent treatment is the biggest concern that we have around any reconfiguration of the service and I and my colleagues have made the point repeatedly in the working group, and that is….whatever the final outcome of this process is I can assure you

that that particular issue has to be one that has to be dealt with because I don't believe that a solution that sends everybody to England can safely deal with emergency situations. We do have to have something different in place for that. Currently when we have an emergency situation we are able to call on people on site, and to have nobody on site is a real concern if that were to be the outcome. So I can assure you that there will be, that solution wouldn't be acceptable to the doctors on the service that that was taken away. To come to your point in terms of the whole extended family issue, it is a very, one of the things that is different about children's cardiac surgery as opposed to adult cardiac surgery is that often a child and a mother has to be moved very soon after birth and one of the things that has to be central to the decision making process is what supports are there for parents, the ability to have extended family, particularly if things go wrong and inevitably in cardiac surgery things will go the wrong way. So the trauma of moving parents particularly for newborn babies is something again that has to be considered as being central to this process as well.

DS: And yes is the answer on the Dublin question.

Participant: I actually sit on the working group, and obviously have been a part of the consultation document and the process bringing it to where it is now. I am here tonight as a parent, and I have a few things Dean that I would like to bring to your attention. Obviously the transport side of things and the access to services has always been a big concern of mine, and I know throughout the document there is reference to the clinical guidelines for transferring the critically ill child but I've been, obviously I have great interest in this, so I've been looking at other standards that have come about, and actually what I find interesting was that these would be adult intensive care society standards. And basically these guidelines for transporting critically ill adults some of the guidance says that immediate, time critical, lifesaving intervention is required as priority 1, which they recommended an eight minute response. It goes on to say then that other life or living saving treatment required is priority two which is within an hour. Further to that there is other clinical reasoning for priority three which is within four hours and then non-clinical reasoning which is within eight hours. Another document which is the NHS south central ambulance service it's an emergency inter-hospital flow chart for acute trusts. Any by inter-hospitals I am assuming that is between hospitals, and again they have a list of medical emergencies that they say should have, inter-hospital they should have certain timescales. They talk about time-critical timescales which is an immediate inter-hospital transfer, which they talk about neonatal medical emergency and also an inter-hospital transfer within an hour, they refer to oxygen dependent adults and children as part of this criteria, which I suppose a majority of all our heart children would fall into this category. Why I'm discussing this, I know throughout the document we refer to the paediatric intensive care standards which state that retrieval teams should be there within the three hour timescale, my concern obviously, going through these documents, is why are the transport standards for

critically ill adults so different than standards for critically ill children? Why are these falling so far short, you know the requirements for children, so different from the requirements for adults?

DS: Conscious of wandering into areas I'm probably not qualified to speak too much about, I suppose to make a general point, and Frank may want to pick it up, all of the standards you are referring to there are national standards, so there is no reason to think you are comparing apples and pears, they are all set with the same sort of bar in mind. My sense would be they are talking about different types of emergencies. There is actually within that relatively small number of urgent and emergency cases, in paediatric cardiac surgery every year, there is an even smaller proportion of needing to be done very, very quickly. Others there is a timeline of hours, and in some cases days, so I think it's just that we are talking about different things, but Frank might want to.

FC: I think the point that you raise is a very important one in many ways [redacted], because the paediatric intensive care standard is for a retrieval team to be with the patient in three hours. For patients who are sick in other ways then that retrieval team can begin to help that patient. For a cardiac surgery patient, the actual treatments in terms of surgery don't begin until the patient goes, gets to the centre. So I think the paediatric intensive care standards or standards that apply to patients with other diseases are not directly applicable to this, and therefore the important time is sometimes not so much when the retrieval team can get there, but the time that that child can get to a cardiac surgeon is what's crucial. And that's something that I think we need to consider very strongly in all of these options.

Participant: Can I just make another point please? For my own clarity, I have probably asked this question before. In the document obviously it says about children's services with particular complex needs like hypoplastic left heart or transplantation will continue to be commissioned through their current provider in England, then it goes on to say the continued appropriateness of these arrangements will be reviewed, obviously when the minister makes a decision – does that mean, depending on the decision, will those children still go to that commissioned place or depending on the decision will they have to go elsewhere?

DS: As a working assumption we wouldn't see those children going elsewhere, but that's not to say things don't change over time so it's just to acknowledge that's certainly outside the scope of this document. We talk about 140 procedures a year of those thirty or so currently going to Birmingham because they are the most complex end of what are all complex procedures at the end of the day. Our working assumption for now those will continue to go to Birmingham, but over time we may look at a different model, but there are no immediate plans at all to do so.

Participant: I attended last week's consultation and got my eyes opened at the questions and problems and concerns that parents and grandparents [redacted]

have, having a [redacted]. And there's very little knowledge about this consultation out in the public domain, and I wonder how that has been put out there – has there been public information documents put out, apart from the document? Because [redacted] and through different places, and so my question there, and I have a number of questions, is how was that done, and is there going to be enough consultation – the general public and not just parents and grandparents?

DS: It's always something that we would be aware of within the organisation I work for, and other public bodies consulting. We have certainly sought to as I mentioned in the introduction to publicise the processes as widely as we can. There have been adverts in all of the national papers, adverts in all of the local papers, press releases issued around the launch of the consultation both by the department and by the health board. We've had the five public meetings, four focus groups, we've written to 600 stakeholders – if there is something we've missed having done all of that then I guess there is always…..it's never enough sort of thing, but I felt that we'd done all that we reasonably needed to do, and even through the likes of Irwyn's and Sarah's organisations as well I know that efforts had been made to raise awareness of these processes and to encourage people to come along to events like this and the focus groups indeed.

WA: Irwyn has there been enough publicity do you think? Are people well enough aware?

IMcK: I think to a certain degree, there would be one, funny enough I was talking to [redacted] earlier on and [redacted] said that there was in [redacted] local area a notice about four or five weeks ago but there had been nothing since. Well I know what my brain is like, if I heard something four or five weeks ago chances are it may have, no matter how important it seemed to me at the time, there is the possibility that you would need refreshed. Now I'm not…..so I do think maybe it fell down a wee bit in that way but yes [redacted] saw it four or five weeks ago and some other parents saw it four or five weeks ago but possibly it maybe should have been in a couple of weeks or last week to refresh everybody's mind. I know I certainly, from our organisation, and Sarah's was the same, hers put it up online, but again that's not going to get to everyone either you know.

WA: I could reassure you though that there have been some really well attended meetings, and no one has missed and hit the wall.

Participant: Maybe the BBC could help out there as well. It is getting very close to the end of this period. But if there are only 40 documents back there needs to be a lot more back, I'm sure people don't know that. We've touched on the safe and sustainable standards and again reading the document and looking on the internet since last week, I can't see any mention of who the professional bodies were who have approved these, especially from Northern Ireland, in that we are in a unique

position and more demographically changed than the rest of the UK – so was there independent professional bodies looked at these and who set the standards?

DS: Well in terms of the safe and sustainable standards, the UK wide standards, yes there were. I don't have details of that to hand, but the document is readily available on the internet, I'm not sure whether we have it on our own website. We can certainly put a link up there to that. The standards for Northern Ireland are just proposed standards out to consultation. They've been signed off by no more and no less in the first instance than the working group members who are beside me tonight, and in due course by the board of the organisation that I work for and by the department. And they have no more and no less status than that at the minute [redacted].

Participant: And just to reiterate what a lot of other people have said travel by road is a big thing that's mentioned, everything you read on the National Health Service and it should be three hours by road to hospital for all sick children. It shouldn't be any different for Northern Ireland, we shouldn't be made second class citizens for our children.

Participant: The problem I have, and it's great to have all these questions being asked, the main problem I have is I have a crisis in confidence in the role of the commissioners and the people who called this report in the first place. I raised this issue last week at the Belfast meeting. [redacted] who is part of the review team at the very start, is on the record as saying that there is a need to concentrate services – this is before the standards were set and they set standards that strangely enough close units and create bigger units so these were created specifically to lead to closures for larger units. With that in mind and the fact that this was known beforehand when this was called in at the last minute – ten days was it? An essentially short period of time, into Belfast, it was known that this was going to close units, and that Belfast's figures were clear to be seen and knew that it wouldn't pass it, so therefore it was called in by commissioners, confident with the fact, and you said it yourself Dean, that Belfast would never pass the standards, which makes us wonder what is your motive? Was it called in to take away surgery, but you needed something else to handle that? Now when I asked that question last week, [redacted].

WA: Well she couldn't be here tonight.

Participant: Well that's a pity because I wish she could be here to answer it again. Brought up the issue of safety and mentioned three cases were children had died which was an [redacted] because that was over an extended period of time and these children had complex issues where essentially the heart surgery was their last roll of the dice. So [redacted]. And it leads us to [redacted], that's [redacted], and if she is [redacted], why [redacted]? Added to the

motivation of calling this report in at the last minute, makes us question if they ever wanted paediatric surgery to stay in the first place?

WA: Well there's quite a big question there, so shall we put that to Dean? [redacted]

DS: I'll certainly do my best to respond to it – there is no ulterior motive here. I suppose the issue for us as commissioners is I'm not a doctor or a nurse or anything else by profession, but I am fortunate enough to have the job that I have, and in having the job that I have, I am required to ensure and assure myself that services that we commission, that we buy for patients in NI be they children or mummies and grannies and all the rest of it are safe and sustainable – it doesn't matter what the service is, I am required to assure myself of that. The Kennedy review process was a process that had been used in that regard across the water and we used locally to provide that assurance. I think what I said at the Belfast meeting, and I think I have said it at other meetings as well, you know Belfast Trust were never going to be able to magic up enough surgical procedures to be above the 400 or 500 minimum or ideal thresholds, that's what I said. What the review did confirm though was a number of other strengths of the service and strengths that we should support going forward. But that sort of is, in my head that's that and that reached the conclusion that that did, and now we have a very real open transparent process where you have the chance to influence the way forward. This isn't a process where I'm heading off in a darkened room and writing some documents I might have done in days gone by in different careers. This is the most transparent and open of these sorts of process. I'm not saying for a moment that we'll come out of it with necessarily everyone's support, but we'll certainly have a process that you will always see the different stages of this and thinking behind the recommended way forward, which is I think all we can seek to do.

WA: Frank wanted to say something.

FC: You raise very important issues, I think the key decision that has to be made going forward from here is the Kennedy team came and they could only make one conclusion because of the numbers issue the recommendation was always going to be as it was. The key thing going forward is whether the minister recognises the unique situation that is within Northern Ireland from all of the aspects that everybody has discussed here tonight as to what we need as a solution that works for NI given its geographical position, given its potential co-operation with other units and not the points made by the safe and sustainable services team to be taken on board – but a solution that fits England isn't necessarily transferable to NI, and that's where the crux of it is really.

Participant: I couldn't agree more that we all trust the clinicians; we've all put our trust in you. But the thing is when you see certainly last week when we were asking questions. In one case, it's been said that parents are being listened to, but it was a

very long meeting last week and things got heated. One of the things that was raised, and it was raised again tonight before I got here, was the splitting the safe and sustainability thing – one is children's lives, the other is a management issue and that was raised in Belfast, and when the point was made Dr Casey came out and agreed with that, and said that there is an issue dividing this and as the debate went on, as people made their cases, it came back at the very end where Miriam and yourself Dean essentially said 'safety and sustainability is one in the same' in the space of a meeting our opinions had been dismissed. So how can we have confidence that you made the right decision and this isn't just some sort of show trial?

Participant: There's one thing this consultation has done and it actually made history in Craigavon council because I think it was the first time ever that a motion was backed unanimously by the councillors in Craigavon. It crossed all political divides because it is such an issue, and people do realise that this wouldn't even be happening in England. To suggest in a room like this in England, to suggest to an English person we are going to put your child on a flight and fly you to Belfast – do you think that would be acceptable? I know for a fact it wouldn't be. So why should our children be put on flights and flew to England were it is not safe and has been proven not safe. The reality is [redacted] – they are living proof that the Belfast centre works so instead of taking the centre out of Belfast, we should actually be investing in Belfast, and if we need to bring in Dublin to sustain it, certainly yes, because that's the reality of the situation we are talking about children's lives. It's all right to say 400 here – it's all right for people to talk about numbers and figures, but that's the reality here and the situation we are in so even the consultation it needs to be brought, people know what this consultation is going to say. To suggest to fly children out is not even on the agenda and I hope Edwin Poots listens to that and it's not a case of number crunching and figure crunching.

Sarah (Children's Heartbeat Trust): Just a point that Dean had said which was that the working group didn't think that we had a shortage of time. I think that's quite misrepresentative of the Children's Heartbeat Trust position, we actually said a number of times through the process and it is minuted which is on their website that we had serious concerns with the timescales of this process, and did feel that it didn't allow the entire opportunity for all the issues to be discussed and that's coming to light at these consultations where lots of different issues have come up, that didn't come up within the working group. And that actually leads me on to our second point in the consultation document as well it says that the standards are endorsed by professional bodies in the UK. Now we have sent off letters to all those relevant professional bodies asking them whether they knew that these standards would be applied in NI. To date we have had responses from the British Psychological Society, and the Royal College of Obstetricians and Gynaecologists to say that they didn't consider Northern Ireland within these standards, and we are awaiting further responses with interest.

WA: There have been a number of issues raised at these meetings that you and your colleagues have admitted that haven't been considered before, and that's understandable. That being the case, is there enough time now?

DS: I think when Sarah refers to the time issues that were raised there were time issues raised in relation to the time that we had as a working group to produce the consultation document, and what got squeezed effectively was everyone's time, the members of the working group had to put in a huge number of hours to deliver that. Unless I've missed I don't think that anyone has ever suggested that the time for the consultation process has been in anyway less than it should be. Twelve weeks is the standard time to consult. The time for the working group, and I'm satisfied, and I believe that the working group members are generally satisfied that we put into the public domain for consultation a fit for purpose consultation document. Other working group members can speak for themselves, my sense was we did, it was certainly a document that was agreed to go out to consultation by all members of the working group. Am I surprised that there has been other issues that have been flagged up, like the one you mentioned? No I'm not. If it was perfect then why would we consult on anything, if we thought we knew all the answers and we thought of every single nuance of every single issue, it would be a strange process. So I'm reassured that some of these issues have been flagged up and I would say again, I apologise if on that safe/sustainable thing, if we think we haven't covered it all, I've certainly done my best to answer that. You mightn't like the answer, but I've done my best to respond to that. I suppose that what I would want to leave you with tonight is a sense that as we will do in the working group that will be explored further and that we do seek to see what we can do with that. But I've expressed my view on it that they are two sides of the same coin – there is no point in it being safe some of the time, and not other points. It needs to be safe and resilient and sustainable to be truly safe. But happy to hear the views of working group members and we certainly heard the views of the folk here tonight.

Participant: There are just a couple of points that I would like to raise as well. Bristol hospital is now being reviewed by the IRP on the safety concerns. Now Bristol was involved in all options of the safe and sustainable in England, and is now potentially unsafe. How can this expert panel be considered credible and the other point I want to raise as well, on page seven of the consultation document, it states:

'This ongoing care which includes investigation, diagnosis and ongoing review is a central component of care for children with heart disease and this service will not only remain in Northern Ireland but steps will be taken to explore its development to ensure that service excellence can be achieved and maintained.'

I would just like to ask how can that actually be achieved if surgery is taken away from Belfast, would you not agree that would maybe be a disingenuous statement?

FC: We touched on this a little bit earlier in terms of the concern of maintaining the level of skill and care in the absence of a surgical unit, and it is a real concern the whole issue of maintaining safe services. Whenever we think of safety there are two aspects to safety – there's the safety of the surgical service but there's the safety of the whole service. And that's what's difficult to rationalise or get a whole, whenever you remove a surgical service you might transfer it somewhere else, you might do that with the thought of making the surgical service safe, but you leave safety issues behind then, and that's what is the biggest issue in this whole process is, how to get a balance of safety between a surgical service and all the other aspects of the service. [redacted] raised about to get a child to have a safe operation, you have to get them there safely, they have to live long enough to get to it, so those are the aspects of the service that are really crucial to get right.

Participant: I just wanted to say that we had [redacted] and then we realised [redacted] wasn't well – but I couldn't have done that and went to England, I suppose as a parent I needed my mummy and daddy and everybody else around me to get me through that, and I hate the fact that we all have to sit here and defend a service that [redacted]. That's what you have done is give me [redacted] back. What I want to know is, ideally as we want it to stay in Belfast, we are talking about 90 – 100 surgeries – would a good surgeon really want to go and work somewhere that there is only going to be 25 surgeries for him to work on? If you are talking about working time and covering hours and 24/7, because we don't want just any surgeon, we want a good surgeon in Belfast – would they actually come and do that?

FC: No surgeon could maintain their skills doing 25 operations a year so a model of care going forward that retains surgery in Belfast would have to have surgeons who are based in Belfast having the opportunity to work within a bigger team, and the only workable model with that would be with surgeons interchangeable between two hospitals where they can achieve the workload. Because you are quite right, surgeons do need to maintain their skills, particularly as things become more complex. They need to be doing at least 100 operations a year, and the only model that can deliver that is surgeons who can, if surgery is maintained on the island of Ireland for all the children then it has to be considered the surgical workload for the island of Ireland as one group and not two separate groups.

Participant: Does that mean 100 operations on children or could it be on adults as well as a mixture? Could a surgeon not do children today and tomorrow adults?

FC: It's a good question, the skills that are required to treat a child with a congenital heart problem are very different from those that are needed to operate on an adult say who has coronary artery disease, but one group that does often get forgotten about in this whole debate are the teenagers and young adults. Because what has to be considered in this process is that if you stop surgery for children in Belfast, you also stop all surgery for teenagers and young adults who are now grown up with a

congenital heart problem. So to answer your question, the number of congenital heart operations can be made up of older children, young adults who have congenital problems, and most surgeons who operate on children also operate on that age group.

Participant: This question is to any of the panel, out of the average 140 surgeries that would be being sent over the mainland, would surgery be ceased here – what sort of figure, where do those figures fall into? Do they fall into England's figures because the surgery is carried out there, or do they remain as Belfast figures so to speak, so if there's any deaths or anything like that from Belfast, is that out of 140, so would that percentage be reflected as you know 14 out of 140 is 10 %, or is that 14 be out of a bigger number that would be being carried out over on the mainland?

FC: If a child travelled from NI to Birmingham and didn't survive the surgery there, that mortality would be counted in Birmingham's surgical figures.

Participant: To me that just sort of worries me that that would dilute the, what the real figures are as such, you know, which means something that I worry about, it's nearly like we are trying to offload something that's a problem here and put it over onto the mainland where it will be hidden as such. It's like brushing it under the carpet so to speak you know. Another question I had, just as Dr Casey was saying about teenage patients which was another question I had to ask about. You have 140 operations which I'm assuming are carried out, but it's removed and you have other surgeries which we discussed at a previous meeting which required anaesthetists trained in cardiology and all the rest, once that deskilling comes into play, that means you've got more than 140, so you might have upward of 200 over the years to come. Coming into the future nearly causes a bigger problem because you are sending more and more every year.

FC: The numbers are greater than it looks at first sight, because there are maybe 140 paediatric cases that are this year in Belfast there were 46 teenagers / young adults that were operated on. The other aspect of the service that is tied in obviously with this is the cardiac catheterisation service so when you count all of those numbers it does mount up to a very significant number of patients who would be travelling back and forward on a daily basis.

Participant: Just looking at the options that are on the screen in front of us, well we already know the scenario around Belfast, Dublin we understand is almost at full capacity at this moment in time, because of the judicial reviews that are probably being undertaken at this moment in time in GB at the minute, how can the panel and the HSC board make a credible recommendation to the Health Minister within the time frame that they are talking about because obviously the judicial reviews are going to push that out? With Dublin, how much discussion has taken place regarding how much capacity problems they have, and what they may be able to share with Belfast in terms of capacity and capability? What has been done up to now? And I

think it's just really a little bit premature that there should be a decision made and a recommendation made to the Health Minister before those answers even fall out of the basket.

DS: To pick up the GB, my understanding today is that there have been no other judicial reviews yet, but Frank was indicating that is a potential outcome down the track of, if the decision is made, if the final decision is made to stick at the number seven, either one of the three existing units or the another unit would be unhappy with that outcome and there is a risk of a judicial review. In terms of the Dublin position, over far longer than this process, over several years and coming back to the point that was made in terms of the forward planning of this, over several years and going back to the beginning of this century there have been efforts being made to get some sort of all Ireland network up off the ground. I think the current situation gives added focus and impetus to exploring that, and you are right as we touched on earlier on. Whilst Dublin does provide care in a number of urgent and emergency cases for children in Northern Ireland at the moment it wouldn't be in a position today to respond to the less urgent cases from NI without an expansion in capacity. So there is active discussion with them in that regard to tease that out. Frank was at a meeting with me a few weeks ago, there's another meeting planned in the coming weeks to talk to them about that behind the scenes a lot of work is being taken forward by them to explore the options. There probably is the potential over time for them if it was the Minister's decision to take on board considerable additional activity from NI. But today, as working group members know because I have shared this with them in terms of the response we got back from Dublin, today they are saying that whilst they can respond to the urgent and emergency cases, they can't respond today to the less urgent cases if that was the decision taken by the Minister going forward.

WA: Irwyn do you believe that all Ireland network can be put in place?

IMcK: I do and basically as Frank was saying too about the judicial review I think as parents we would nearly hope that there would be a judicial review in England because it just may hold the minister back a wee bit in saying 'we'll make this decision on 1st February' that will say if they suggest a review we can't make a decision here. I believe there are steps afoot in Dublin to improve their situation and my hope would be that given that wee bit more time – at this moment in time they'll not take all our surgery, I think we've got to acknowledge that fact, but hopefully in the future they will be in a position to take more of ours, and that if given a wee bit more time that may be possible, and that's what I would do, you know as parents. Parents have spoken to me about this and the ideal thing would be to, as someone mentioned here about family support etc, it's a lot easier to do it by road than it is by air. And I do believe that given time, the Dublin option would be viable.

Participant: Sorry, I didn't think that the Dublin option was the option to move services away from Belfast?

IMcK: No, just we were saying about not having Dublin or Dublin not being available at present, I think Dublin will be available, but we've said all along that Belfast as a standalone service won't work. And that the real importance of this, regardless of what, even forgetting about England, we need to sort ourselves out. I think it was [redacted] mentioned that at the very first meeting we had here, we need to sort ourselves out here. We are ourselves, we should be working on some sort of arrangement for ourselves for NI children, and we have stated all along that Belfast and Dublin was the place to go. And I do believe that at this particular moment in time it won't work, but given time it will work.

Participant: It's a reciprocal relationship, they have capacity.

IMcK: Well, I think to me that would be the ideal situation, but whether that can work or not, I think I would leave that to see if Frank would say if that would work or not.

FC: The thing that, the proposal of redividing the surgical workload is one that we have had discussion with and intend to have more discussion with colleagues in Dublin. All of those things are still around the table in terms of, because you know as someone who works in the service in NI we feel that we could provide very good care who would come in the other direction. There has to be a willingness on both sides to make that work, and reality is that the bigger centre always wants to draw things to that centre. And it does come back to seeing what we can practically deliver, and we would dearly love to work the model that you proposed if that could be achieved.

Participant: I just wanted to say that I totally agree with Dr Casey in that [redacted] had a lifesaving intervention procedure and cardiac surgery [redacted] years which is brilliant, but we totally have been forgotten about in this whole process, and I sound like a broken record because [redacted] as well and I'm aware of that but I think it is important to realise as teenagers and young adults we are still patients our care is still ongoing [redacted] but your care continues, and I think that has totally been forgotten about. Another point I'd just like to ask Dean about actually is that last week at the Stormont meeting, when Miriam spoke about the focus groups, her and Dean on occasions referenced that the teenager and young adult focus group, and that is totally not what I got, I sat in the focus group, a parent lead focus group because there was no focus group that suited my age. Now I did email them the next morning after that meeting in Stormont, and I'm still waiting for a reply. But I think it's really important that young adults and teenagers as patients are still considered in this process, because I can assure you that I have quite a lot that I would want to say, and as a patient I know what it's like to be the one that's in the hospital bed.

DS: Starting at the end and working backwards then, if we've missed an email coming in, if I haven't seen that email, I'm not sure who that came into, I don't think

it's too late to sort out the issue. Certainly the group is not forgotten about, they are clearly referenced in the document, as Miriam mentioned at Stormont there is a focus group specifically planned for older children / young adults. I don't think that, Rosie, I don't think there is an age limit on it.

RB: I don't think it has taken place yet.

Participant: I did email and they emailed me back and said I couldn't sit in the teenager one because obviously I'm not a teenager and so I sat in the focus group in Portadown, but I think that it's very different to sit in a parent focus group when you are actually a patient.

RB: My apologies if that was the case, and if it was anything to do with the trust then I absolutely apologise that was never my understanding that there was going to be an upper age limit on that. But I'm quite happy to pick that up with the board tomorrow.

DS: It may be that the email came into the trust, but because of patient confidentiality we, that was just to Rosie and colleagues to look after, but in principle unless I'm missing something I see no reason why you would be more or less able to take part in the discussion than an 18 year old who had surgery.

Participant: It was just about, even for the likes of small procedures, that the cardiac children needed, for the likes of even, [redacted] and something that I wanted if Belfast wasn't there. Dr Casey, what would happen to [redacted] from the cardiac point of view going into hospital, where would [redacted] have to go?

FC: There is certainly a consideration there, particularly for children with complex heart disease, who have to have other procedures I suppose I don't want to specifically comment on [redacted] but I'm happy to have a chat with you at another time about that in terms of confidentiality. One of the many factors that needs to be considered in this as was raised at other meetings are those children with complex, multiple problems, you know who need other procedures and the skills that are needed to deliver that, and the skills around delivering anaesthetic to cardiac children, so that is a real consideration that we have raised in this process, and even today actually we met the medical staff in the children's hospital to discuss this issue, and one of the topics that was raised at that meeting was that very issue so it will be brought forward to a discussion over the next few weeks.

Participant: Yes it's just these small procedures, mightn't seem like a lot but if Belfast is taken away, then these children need this service for other small procedures.

WA: And yes, we heard from other young adults that they still have to go in there to get their teeth done.

Participant: My comment really follows on from [redacted] comment, and I just want to know what happens with the future of the Clark Clinic services if the children are sent to Birmingham and they come back and they need care or surgery in the Clark Clinic. I know, [redacted] so any problems or issues that service is retained, so if there's a complication or the child needs in again for a minor procedure or anything at all complications, do you put them on a plane and send them straight back to Birmingham? That's not practical, we've heard very passionate pleas from so many parents here tonight and the implications for their family life so could you tell us, outline tonight what's going to happen to the Clark Clinic? Will it still be there to look after these children with any other complications or even minor issues that will arise?

FC: It is very important to clarify that the issue that's being discussed at the moment is just the surgical service. But having said that, the implications for the future of the rest of the service are as we've discussed. There is no plan in any of these scenarios to discontinue the paediatric cardiology service, the consultant team and the nursing team and all the other professionals would continue to work in that. In our view we would be working in much more difficult circumstances than the kind of point that you raise about a patient coming back from another unit and developing complications and the team not have the surgical skills is a real issue. But, when we're thinking about the model of care that we would prefer, we do feel that in some way we need to have collaboration where we can have access quickly to surgical care, and the model where others input as speedily as possible is the one that we need to try and achieve. It is important to reassure people because I think that other parents have said to me is the Clark Clinic going to shut its doors in the springtime if the Minister's decision should be that surgical goes to England, and that is certainly something that we don't envisage happening.

Participant: But can you guarantee that that isn't going to happen, with anaesthetists as well if complications do arise that these children will receive the care in NI?

FC: I'm not making the argument to take surgical services away, and your concerns are our concerns. I have to be fair to my colleagues in commissioning that throughout this process I think that perhaps they have begun, through all of the input from this kind of meeting, to take on board the complexities, and I think that when we do come in the springtime to try and discuss with the Minister what the best way forward is, it will be a much better informed decision than it would have been six months ago. And that's thanks to people like yourselves who come out, and the most important voice that's listened to or that says much more eloquently than I can transmit in meetings is hearing from you as parents. So you should, I think, consider that your views are valued within this process.

Participant: Just to conclude tonight, mine's a plea for recognition to be taken on board of the uniqueness of Northern Ireland and I suppose there does seem to be

scant disregard in relation to the period of the consultation process here as opposed to England, the length of time that the consultation team spent in NI, and even the one hour Skype conversation that you had with Dublin. It just doesn't seem substantial enough to give you confidence in the actual findings that are coming through. The fact that the review of findings are being reviewed themselves in England – that alongside a lot of the issues, and the key one tonight seems to be the impact of transport. I meant the access to services – we've got a state of the art service but if you can't access it, it doesn't matter how good it is. We did talk about the appropriateness of the criteria, the weighting, the type of the criteria and given the fact that the length of time spent on this here has been a fraction of what has been spent across the water. I think that needs to be turned on the head and needs to spend a bit more time, if the challenge on the review in England gives us that we need to explore that in terms of the actual uniqueness and build our relationships between here and Dublin because, this is a life or death issue.