Paediatric Congenital Cardiac Services Consultation

Public Meeting 26 November 2012

Everglades Hotel, Derry ~ Londonderry

Panel members:

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

WA: I wanted to start off with the service specification aspect of it.

P1: My name is [redacted]. I have a question that I would like to put to Dr Casey. In terms of clinical engagement, I am wondering from your point of view as far as this process has gone up until now, can you describe to us how you feel clinical engagement has been a part of that?

FC: To step back a little from that, this is a process that I think is crucial, that everybody is involved in – clinical engagement, parental engagement, the engagement of those who are going to make the decision about the future of the service. At this point in the process, we feel that we are closely involved with the process now as part of the decision making process, and I hope this consultation process. All of the working group that meet I think have very diverse views as to what the final solution will be and I suppose as a clinician that's where I have to make my views known and my fellow members on the panel will concur that we don't always agree on what the final solution would be. We have had our differences along the way in terms of what the way forward is but I think that this issue is now so important to the future of all of the children who are born in NI with heart conditions, not just now but for generations. It will be crucially important to have clinical input, to have your input as parents, and it is fair to say that the process as it has evolved has become one where the parental input in particular has been more recognised than maybe it was at the start of the process and that goes right back to the safe and sustainable review process that was done. That was a particular process that we as clinicians had concerns about in the way that that came about and the way it was conducted, and indeed the consideration that Sir Ian Kennedy gave to the unique situation of NI as a geographical entity. The Kennedy review has been done, we've moved on from that now and the next few weeks are crucial in terms of the input that comes from everybody so that when the time comes at the end of this consultation process, that everybody has had a chance to make their views felt and those views are fed then in an appropriate way to the minister so that he can look at this service

not just as a surgical service and a surgical issue, but all of the elements that make up for a good lifetime care package for a child with congenital heart disease. That's where I see the direction of travel from here.

WA: It's the first time that Frank's been able to come along to one of these. One of the issues that was raised both in Ballymena and in Enniskillen, was about that a lot of parents felt that they were listened to more in the Clark Clinic. They had a close relationship with the people that they see all the time in the Clark Clinic and they completely understand that sometimes you have to go elsewhere but they felt that close relationship was lost and they found that pretty difficult.

FC: That is one of the big issues for parents. There are things that are good about having big units, but there are also things that are good about having smaller units. We are very fortunate that we have a superb team of nurses and other supporting professionals within Clark Clinic and they do build up relationships with families and parents – as do we over many years. The prospect of going away to other centres understandably causes parents extra stress, that is why the support for parents is crucial in all of this and the access that you mentioned early on in terms of parents having access to people that they know is something that in a future model parents are very worried that they would lose that.

WA: A lady at the front.

P2: My name is [redacted]. I wanted to talk to Dr Casey too about the different types of surgery that are going to get sent away to England and other places. Is it going to be all surgeries or what is going to happen to minor surgery, because as you know [redacted] and [redacted] is going to need surgery maybe [redacted]. Would we get sent to England? That is a minor operation compared to some of the surgeries that other children have been through.

FC: To come back to the process that is going on – I am not avoiding the question. As Wendy said at the start, no decision has been made and the options that are outlined in this consultation document – all of them are open. Those options range from some surgery being done in Belfast and Dublin or UK, or all of the surgery going out. The reason why I want to be involved and represent the clinical team, is that we want to bring our view as to what we feel is the best option for parents and for children. I can't answer your question as to what the outcome will be – this hasn't been decided. For things like [redacted] I fully understand your concern, that for something that is not major that your child would have to travel to another centre. That is one of the options that is in here, and we made sure that one that was strongly considered is the retention of some surgical services within Belfast. We start from a blank sheet of paper and given all of the considerations to bear on this decisions to what can give the best overall package of care.

MMcC: Just to reiterate what Frank has said – there are a range of options. They explore quite a number of different scenarios from surgery in Belfast, Belfast and

Dublin, Dublin, GB etc. This is the opportunity for you to shape the future of that by telling us what you think; whether those options are reasonable or whether we have missed any options that could be explored. We will within the working group have the opportunity to analyse all of those afterwards and try to make a considered view as to what would be the best way forward. That will ultimately be a decision for the minister. But we will be taking account of all of that.

WA: We will come a bit more to the options in a minute.

P3: My name is [redacted]. I am the [redacted]whose life was saved at the Royal because of [redacted] heart difficulties. When we came in tonight, we were handed some forms to look through, and if we didn't want to contribute verbally here, we could fill them in. I have to say that I found the forms very confusing. You would have to be an expert on everything that is going on in this process. I am not an expert. A lot of the people here tonight who have children, whose lives have been saved and are being saved on an ongoing basis are not the expert in this thing. The Heartbeat Trust people here held a public meeting in September in the City Hotel here and it was packed. People had to bring chairs in from another place. The feeling throughout that meeting and the feeling that we as grandparents and parents have got from feedback, petitions and so on which are on 80 – 100,000 all over, is that safe and sustainability is what the Royal has produced over all these years. The reason I believe that this is changing is financial. I know that there are experts up here that will argue that down my throat tonight, but that is what I believe. For me, the primary concern has got to be the safety of our children, those that have already been born with a heart difficulty, those that are going to be born with a heart difficulty, and there is no way that anybody is going to convince me or any of these parents, that sending our children to England, especially new born babies and separating them from their mother is safe or sustainable or right or just or moral. And of course we are going to stand against this and through the demonstrations that we have already had, we are going to continue it. And we have a march coming up in Belfast – this might not be what you want to hear here tonight, but I couldn't care less about that, and most people here tonight do not care about less about that. We are on a road to keep what a magnificent service that the Royal provides, and that's why I am here tonight and that is why these people are here tonight.

WA: Dean?

DS: You made a number of points there [redacted], and just to come back to a couple of them. The complexity of the consultation – I think Wendy had mentioned in her introduction and Miriam the same. It is not the usual consultation process; not the usual consultation document with the recommended option. We have sought as far as possible to keep the documents straight forward, but I think we would all hold our hands up as working group members, that the area is inherently complex and despite the very helpful input from all of the working group members, the document

is trying to capture a range of complex issue. As Miriam said in her presentation, if you distil it down there are three core things that will provide a framework within which a future decision will be made. The first is the service specification – the description of the ideal service regardless of how that is actually provided in practice, the various components of that. The second is the different options for providing that service. And the third thing that we are consulting on is the ways of measuring, comparing, valuing the different options for that service is what we are consulting on at the moment. We sought to keep it as straight forward as we can but I think the point is a fair one, that it is still inherently complex. The finance issue is an interesting one as well. That has come up in all three of the public meetings so far. I have responded to it in all three of the public meetings as well. To speak very straightforwardly – I keep it off my pen picture in case it sends the wrong message, but I am an accountant by profession, but I keep it off my CV because that was a long time ago now. But in straightforward terms I can assure everybody in this room that the cheapest, least costly option by some stretch would be to continue doing what we are doing now with the service provided in Belfast. Any other option would be a more expensive option. For the avoidance of any doubt on this, this is not about money. This is about providing safe, high quality, sustainable services for children now and in the future.

WA: [redacted] –

P1: But why is the proven, safe service that we have being assessed with criteria that aren't suitable for NI? And surely it would involve money if there were areas which need to be addressed in the safe, excellent service that we have? Enhancing that service by investing in it would require money. And why is that not being an option as opposed to shifting this problem, as I believe the trust are seeing it, across the water? Our children – their lives have been saved for years, and they will continue to be saved by this service and the dedicated and committed team at the Royal. At the end of the day if the Health Minister was to pour money into that and enhance and strengthen the network with Dublin, why are we going through a process of being assessed by a criteria that has been suspended in England and Wales? Why are our children being guinea pigs?

DS: Just to comment on part of that, and Miriam may wish to comment on the across the water position. The draft service specification is just that – it is a service specification that members of the working group including parents and parent group representatives have worked up together but it is a draft service speciation. If the view of yourselves or others is that there are elements that are not correct then we would be very keen to hear that. But it is a draft. I think that the point in relation to the services in Belfast and that option are well made. If the Belfast option was to be viable in terms of its ability to respond to that service specification, there would be a need to invest in that model, but the practical difficulties are that you can't change the number of procedures that are undertaken within Belfast which brings us back around to.

P1: But the number of procedures each year – why does it have to be based on criteria which were designed for England and Wales? We are a geographically smaller region. Why are we using that standard for us in NI? We don't carry out that many operations, but that doesn't mean that these operations are any less lifesaving? Can someone please answer that question for me?

MMcC: Maybe I can try to answer that. The service specification firstly, we do invite your comments. If there is something that you feel should be added to that, or changed, we'd welcome that. An element of the service specification, particularly around the safety and quality and some other aspects is based on the safe and sustainable standards that were developed a few years ago. They were developed with the intention of describing what any child undergoing paediatric cardiac surgery or interventional cardiology should have access to. Those standards were supported by all of the major UK professional groups, and indeed supported by parents groups, I think Irwin's organisation had been involved in the development at that time. They are not designed for a geographical area, they are basically designed around what professionals across the UK feel is correct. In terms of the numbers, and they are not driven by numbers – I should say that at the start. What they describe is a service that they would see if a child needed to have surgery for example, a service that can respond to those needs 24 hours a day, seven days a weeks, 365 days a year. In order to do that, you need to have a surgeon available at every hour of the day. In order to have a surgeon available in every hour of the day, you need probably in the region of four surgeons as a minimum, and the expectation is that each one of those surgeons need to be doing at least 100 procedures to keep their skills up and to keep their experience up. Surgery and small children, paediatric cardiac surgery is hard and Frank can provide an awful lot more detail on that than I possibly could. But they need to do about 100 procedures and ideally the figure is 125. So if you have four surgeons, each doing 100 procedures to have a unit functioning, every day of the year needs to do approximately 400 procedures. So it is not the numbers that are driving it – it is the size of the team that is providing the service, and the needs of that team to be performing a certain amount. All of the evidence is that the more procedures surgeons do, the better they are; and the better they are, the better the outcomes are for children on whom they operate. So that is the underpinning principles – that description of numbers. Does that make sense?

P1: So, according to your answer, then only children in Northern Ireland have to be assessed by this criteria, because hasn't it been suspended in England and Wales and rejected in Scotland?

MMcC: What's happened in England, actually in England and Wales, and I know that it is quite a complex situation and it can be hard enough to interpret what is going on. The standards were developed a few years ago and the standards were endorsed. There was then discussion around what should currently happen, particularly in

England where there were 11 centres doing cardiac surgery and really 11 was deemed to be too many for England. Oxford then closed so there were 10 centres. And there was a decision taken that was announced on the 4th July that for England, the number of centres should decrease from 10 to seven, and that three centres should close. The three that were identified for closure were Leeds, Leicester and the Royal Brompton in London. There have been challenges against that decision, to close three units and maintain seven for England, and that is currently being reviewed. There were challenges, and on the basis of that, the Secretary for Health Jeremy Hunt called for a review of that decision. But it is a decision about how many centres there will be in England. It is not a review of the standards, and that is somewhat separate.

P1: And yet our children effectively are currently the only ones subject to these standards.

MMcC: Well, what we are doing in the consultation, we are asking you 'what are the right standards?' We have put standards in the consultation, and the working group is saying that those are reasonable standards for children in NI to expect, do you think they are right? Do you think there are additional standards, or do you think different standards should apply? So there isn't a decision on the standards until the consultation ends and we either accept them as they are, or we amend in light of your input. There is no decision at this point about what standards will be applied.

WA: Frank, would you like to say something about this?

FC: [redacted], your point on the numbers is a very important one. The processes, as Miriam said, have evolved from this figure of 400 operations and the primary driver between that was in terms of a rota for a surgical team. The question is, is 400 a magic number? That's a controversial conclusion, it is based on the rotas for surgeons, but in other centres across Europe the numbers are not 400. The important thing is the quality of output for our children in NI. The primary criterion will be what their outcome from surgery is. I think that the numbers in NI are a challenge for us for many years, even preceding safe and sustainable services, we had looked at what options would be to deliver surgery in NI and had to look at ways that the service could be supported so that we can address some of the issues that Miriam has highlighted in terms of 24 / 7 cover. To let you know where I believe this is – we have to keep our mind open as to whether there is some way that we can provide the safest surgery in NI. If that does in the future consist of surgery within NI, then we have to be happy that those children do continue to get the high standard of care that they have got in the past and that that is securely covered with a surgical rota. The big challenges in providing that within NI, if it were to be a realistic option, it would need to be supported from the surgeons in ROI. We have to find our way through this in a way that it can satisfy the safety concerns that people in commissioning this service have, knowing that those of us who work within the service are, we hope, our record has been in providing a safe service up to now and

in 2012 we have to face the challenges that brings for the future as the working hours of surgeons and everybody else changes. I would encourage all of you to continue to make your views known in the way that you have so that whenever the final decision is made, that the issues that concern you most are to the forefront here, and then that we can balance those issues against what is the right decision. What I wanted you as parents to be sure of, is that I am not blinded to any solution. I think that we want to make sure that whatever comes out of this, that the good parts of what is being delivered are not damaged by a decision ultimately, but yet we have to make a plan that is secure, that is sustainable for the next 20 – 25 years and beyond. That is where we need to get to.

WA: It is interesting Frank, if you don't mind, it is something that just occurred to me that came up when we were in Ballymena last week and it was with the [redacted] who was still being treated at the paediatric cardiology unit and [redacted] and a couple of other teenagers who were there were talking about the fact that perhaps, since we are asking here are the proposed standards appropriate, are there other areas which should be considered; and they were suggesting that meeting future needs ought to be in there as well.

FC: I think that is a very important issue, because when we talk about surgery, we are focused on paediatric cardiac surgery, but there is a whole generation of young people who had surgery as children, and now are adults. And the skills that are required to operate on a young person who has previously has had heart surgery as a child are a very different set of skills to those surgeons who do coronary heart bypass surgery. So the two things are very much interlinked and it is something that does need to be factored in to the impact of any decision as to what we are calling cardiac paediatric surgery but the teenage and young adult population is one that is going to be increasingly important and I think in England that is already something that is being recognised that will need to be factored into the future planning of service there. Again particularly important in this area where in the absence of a surgical surgery in Belfast, those young people would have to go elsewhere as well.

P2: You are saying that the outpatients and appointments in clinics are not going to be affected by this, can you assure us that the like of Dr Casey and other cardiologists are going to stay in the Royal because the way most of us parents are thinking, why should they stay if they are not fulfilling their jobs and their needs? They have worked for 20 – 30 years to get to this position, just to be going to doing routine check-ups and stuff? Why should they stay? If they can't do the interventional cardiology, they would do the caths etc every week, and they are always on hand if something does go wrong – I have known plenty of children and new born babies that have needed surgery and have needed things done straight away that would never have made it to across the water, even to Dublin, and have had to have surgery straight away. So, our fear as parents is if these services are taken away from the like of Clark Clinic up in the Royal, we are going to lose our

cardiologists that we have put our children's lives in. We are going to lose them too. Can you assure us that they are going to stay?

WA: Is that a bit of a challenge?

FC: Are you asking me?

MMcC: I suppose if I pick up first, at the risk of embarrassing Frank, we can't really ask him to comment on his own position. I know that we have an exceptionally good paediatric cardiology service and remember when [redacted] was there and has built it up from that time; we've a long history of a really good service, telemedicine at the forefront and lots of other innovative things. What we can say though is that service is not under any consultation. We are not proposing that service should be diminished in any way. Ian Kennedy in his report said that the service was provided by a dedicated and committed staff and that it had the potential to be a model children's cardiology centre. We are therefore not suggesting that there should be any change but actually in time it will need to be developed and enhanced, and perhaps with a growing need that would be appropriate. What actually happens, what individual decisions are made is always impossible to predict and it would be wrong of any of us to predict, but the vast majority of the work that is currently undertaken within Clark Clinic and the surrounding patient appointments, and indeed the visits out – I am sure a number of you will see Frank and colleagues in Altnagelvin and not have to travel to Belfast. We would see that as remaining. In the options contained within the consultation document, there is relevance to the fact that interventional cardiology needs to have surgical cover. All the guidance suggests that interventional procedures should not go ahead without the cover of the surgeon nearby on the premises. And we do about 40 interventional procedures in children under the age of 16 per year. If that were to be affected in any way, we are aware that this is a group that would need to be looked at. But that is in under one of the options, and again there have been no decisions on this. We are open to those options and it is important that you tell us what you think of those and how realistic they are. But it is as great an assurance, without predicting what individuals will do in their own work life balance etc that is the assurance that as commissioners we can provide at this point.

WA: Rosie, I just wonder if you might have something to say about that, because it all applies to your dedicated nursing team too, they're no different to the doctors, they want to hone their skills and be as good as they can be at what they are doing – what is the view from there?

RB: They have been kept up to date it is fair to say and would have been anxious at the start of the process as everybody was with the uncertainty. I think I am alright to speak on their behalf to say that they recognise that they are valued and a part of a very important team that we anticipate to be there for a very long time.

WA: Dean, I think you were itching to say something.

DS: It was only just to build on what's been said already that as well as individual options and exploring this as an issue, it appears, without getting ahead of the evening, in the criteria to assess the different options, one of the specific criteria that is identified is that whatever option would be considered for it to score well, it would need to facilitate exactly the sort of thing you are describing in terms of providing support to the cardiology team to ensure that the services that are there now continue to flourish as before.

WA: Frank, will you stay? That's what [redacted] is asking!

FC: I will decide in the springtime! I would very much like to stay. I and my colleagues have put a lot of our lives into the unit and we do want to see the expansion and development of the unit to provide good and new services in the future. I do recognise that the actual size of the surgical service is a huge consideration in 2012 and all of us find this very difficult in terms of trying to match up what can be delivered within NI going forward in the future to try and make that comparable to what is delivered in the larger units. As I said earlier, larger units in terms of surgery are the direction of travel. We have to look at what model can work for NI; we know that even though the service worked very well in the past, it depended on a very small number of people. If we are to move forward in the future with a surgical service it needs to be dependent on more people so that it can be secure and I would like this process to be as imaginative as it can be within the parameters that we have to work within to see what way it can be delivered so that when we come out the other side in the springtime that we can present the minister with what is a workable for NI.

WA: I think Frank is pointing us on to the next section. On the basis of what you were saying there [redacted], and [redacted] as well, perhaps and this is just me suggesting it, another element that might be even pencilled in around the service specification is the retention of dedicated and skilled staff which would maybe fit into sustainability.

FC: It is a big issue – the issue is to how we do retain the team that I am part of and not just the doctors, the doctors are sometimes the least important part of the team, all of the nursing and the other staff who go on to make up that team. I think that that is very crucial in considering the impact of the decision.

WA: I am just going to move on to the next slide because I think we are there – what Frank was talking about, the different options for where and how and many of you want to talk about that. There were questions asked at the last meeting we were at about if emergency cover is as important as it is when you get to the criteria, why is removing cardiac surgery even one of the options that is being considered? There are quite a number of different options there. Are the options appropriate? Are there some of them that you think are a really good idea, are there other options which should be considered? Which ones are the appropriate, and are there other ones which should be considered?

P3: My name is [redacted]. There is a lot to take in tonight, and maybe this has already been answered and has gone over my head. But what about the option of the surgeons coming here to do the surgery? Because they would be a lot fitter and healthier than our children to travel. [redacted] wouldn't have been fit to travel to England. And they wouldn't let me travel with [redacted], I wouldn't have liked to have been left behind. Could you not build in an option where the surgeons travel, so the children don't have to leave?

WA: Is that something that you have considered? It is a fair question that [redacted] is asking, why not get the fit and healthy surgeons to travel rather than the children?

FC: We do have that partly in place that surgeons from Dublin do come to help with the surgical workload in Belfast. The problem with just asking surgeons to travel is that it is not just the surgeon who is involved in delivering the care to children and sometimes in this process we get focus too much just on the surgeon. For a child to do well with a congenital heart problem, they need the input of a whole team of people so they need the paediatric cardiologist, the nurses, and particularly around the time of surgery, they need the intensive care staff so we focus a lot on surgeons, but crucial to that are intensive care staff and the skills that they bring to making children recover and therefore whatever model we come out of in the future, part of the standards that have to be achieved has to be that good intensive care continues. We have been very fortunate to have some excellent cardiac anaesthetists who have done a job that is well beyond the working hours that they are to do, to try and deliver superb care to the children, but in the future, we need to look at a model that doesn't depend on so few people. It is a very attractive concept for surgeons to come in and out but just doing the operation and going away isn't all of the answer.

WA: Not the whole picture [FC: no, it's not]. Irwin, I am conscious of the fact that we haven't heard from you yet. We have heard from Miriam about the numbers of meetings that the working group has had, and the input from parents – I think there are about five different parents' representatives on the working group, but you are the one that is here tonight. What's been the gist of that? What have you been saying about these different options?

IMcK: This is something that I have said from the word go, that the main thing that I wanted to see in was a more robust arrangement with Dublin. It is something that we have been going on about for about five to seven years; there should have been something with Dublin arranged. To be quite honest, what I think is happening is now is not good enough. It is not good enough that I believe there are families now being sent to England that hitherto wouldn't have been sent to England for surgery. What surprised me was that there was 13 interventional cardiology cases sent to England, and for that there should be a surgeon in attendance. I think for us in NI that is not good enough, and I believe that this process should be followed through. These numbers, there will always be children with complex conditions, such as transplant etc, some of those will be sent to GB, that the majority at least should be

kept in the island of Ireland. The figures where there were 90 operated on here and 50 somewhere else is over 50%. There were 13 interventional cardiology cases sent which is about a third and for NI I don't think that is good enough. I feel that this process is going to shape paediatric cardiac surgery for years to come and it is something that the whole package has to get right. And parental involvement, and looking after parents, has to be part of that process.

WA: I am sure there are lots of you who would agree with that. What about these options? The question that is being asked is are the options appropriate? Some of them that you think are and aren't.

P4: My name is [redacted]. We had a child born, and we knew at [redacted] that we had to go to Birmingham and we were told. That gave us time to get ready to go there. We didn't want to go there, but we had to go there. I am not posing a question, our experiences of going to Birmingham, we had to leave family, and prepare our other children and we are lucky that we have two good families. We went to England, the baby got through the surgery and is going well. We had to stay there for almost [redacted]. The safe and sustainable bit as Dr Casey says is not just the surgery – it is the aftercare. We experienced Birmingham, and then when we came home we experienced Clark Clinic. The difference was day and night because of the care in Clark Clinic was safe. Birmingham surgeons were first class, can't say enough about them. The aftercare, myself and [redacted] my wife, never left our babies side because the care wasn't up to standard for us. We didn't know what Belfast was like at this stage, but [redacted]. It is not safe, and if all surgeries were to leave NI now as one of the options, Belfast is what we want, Dublin and Belfast as the second option. If all surgeries were to go to Birmingham or wherever else in England, how long would we have to wait for our child's surgery? If all surgery was going across the water, how long is that going to delay [redacted] next surgery? That is our risk as well, and it is not a risk that you want to be taking with a child's life. There are other risks. We had to fly over and fly back, and on our way back the flight developed problems. On our way back, we had to use [redacted] on our wee baby to keep [redacted] alive to get [redacted] to Belfast. That wasn't safe. It might have been a freak thing, but it happens. You don't want to lose your child because you have to go across the water because we had to go to England. If GB is a risk that we all have to take, the options primarily would be Dublin and Belfast. The aftercare, Birmingham was like a production line. There wasn't enough staff to look after everyone when [redacted] was there. We had to monitor medicines because they were understaffed. They couldn't do the job as well as it is being done in Belfast. There is no way by sending more surgeries across the water that is going to get any better – it is not, because the staff are not there.

WA: [redacted], thanks for sharing. I know this is a very distressing topic, and completely understandably. This is something, Frank, that people are really disturbed about.

FC: That's why we talk about whole package of care, because the surgical event is crucial to the child's survival and in the past we have sent children who have required very specialised surgery to the team that we think can deliver it best to them. The team, particularly the nursing team, that deliver the aftercare and pre-care in Belfast are comparable to anywhere else in the world and our mission in all of this is to try and preserve this and the risk that [redacted] highlights is our concern as a clinical team is how we are going to preserve that in the future, in the presence of a different way of doing things in terms of surgical care.

WA: Thank you, there was a [redacted] in Ballymena last week and [redacted] said [redacted] was one of the teenagers and [redacted] found difficult to understand was that [redacted] has a label that says [redacted] needs special care, and it didn't feel like that when [redacted] goes through the airport. It was a very good way of putting it, and it did bring it home.

P5: My name is [redacted] had [redacted] surgery over in Belfast. It seemed to me that it was suggested earlier that with the 400 surgeries that are needed for it to be sustainable, the four surgeons have to be on a rota, doing so many surgeries a year to keep up their skills, for it to be safe. But it is clear that as [redacted] was saying, it is safer here than it is over in England. How can you say that it is not safe here, when the review said that it was?

WA: It is a confusing one, and it is something that has been asked before, Miriam.

MMcC: It is, what Sir Ian Kennedy's report said was firstly that there were no immediate safety risks. In terms of children undergoing surgery at the minute there are no immediate risks. But what he essentially said, was because of the small size of our service, and the small numbers and the very small team of staff providing the surgical part that to continue to do the surgery, presented a potential risk. And that potential risk needed to be addressed. It seems peculiar on one hand to say that there are no immediate safety issues but what he is saying is that you can't keep doing things the way you are doing things now which is why we went back to the drawing board to consider how best to do things. But he was giving a clear recommendation that the current arrangements were simply not suitable for continuation.

WA: Why is it happening so quickly Dean? Since there seems to be a much longer timescale across the water?

DS: As Miriam says we do have the Sir Ian Kennedy conclusion which highlights the need for change within six months. We have sought with members of the working group to take a process forward that recognises that timeline but at the same time also recognises the need to do this properly with appropriate engagement and producing a professional fairly easy to read document, with the qualification as we said, the pinch point became and members of the working group will confirm, actually an awful lot of work having to be done in a relatively short timescales, particularly around the period leading up to the submission to the Minister of the

consultation document. That was where the pressure was felt in terms of responding to a timeline, getting through a lot of work within a very quick period of time, sometimes with a two or three, or four hour meeting on a Friday afternoon to get through that initial stage of the work. We will continue through this consultation process and out the far side of that with a recommendation to the minister on foot of the consultation process and in due course, subject to the Minister's view on all these sort of things, a recommendation to the Minister on the way forward, we will continue to ensure that there is appropriate momentum in the process. But 12 weeks is 12 weeks. That is how long we have to consult, and unless it is exceptional circumstances, you can't consult in less than 12 weeks. There are some fixed points in this. The reason why we are doing it quickly, or the context for that, is the Sir Ian Kennedy review, but we have to do it properly and we are seeking to respond to both of those.

P6: Looking at that, I would have to go for option four. My [redacted], although [redacted] was here and treated under Clark Clinic, [redacted] had [redacted] surgery in [redacted]. Only this week we have learned that [redacted]. [redacted] is the patient. We haven't had the heart surgery. Surely it should be up to [redacted]? Now [redacted] primary option was to let [redacted] go back to where [redacted] was before, because [redacted] knows those people, what's there. And being in Ireland, it meant that when [redacted] had [redacted] surgery, [redacted] family could visit, and that is a very important part for these people who go through this surgery. Especially when they are kids. [redacted] is now [redacted]. But [redacted] would like to see an all-Ireland option, and surely those are the people who are affected by it. Surely it should be their choice, not Ministers who sit and decide what happens to them. It is their lives.

WA: Might your [redacted] be able to go along to a focus group – they are having one for teenagers and young adults who have been involved?

P7: Yeah, we have heard of that, but a lot of it is in Belfast and it is the travelling back and forth and we travel there for appointments and back; [redacted] does courses and [redacted] is at different things and [redacted] life has to continue on. Sometimes it is quite difficult for us to get involved in things because of where we are. I think it should be up to them. It should be their choice, they are the ones being treated, going through the surgery.

WA: Will you make sure that you put your views in, because we will flash up the details at the end on screen. As part of the consultation, we genuinely do want to hear views.

IMcK: Wendy, I think that is a very important point that was brought up. I don't know whether I would agree if [redacted] should decide where [redacted] is going to get operated on, but the fact that it is in the island of Ireland, family support is so much easier. If you waken up on a Saturday morning and decide that you will nip down and see, should

it be a one, two or three hour drive. Chances are you will do that. You will not sit and say, I will jump on a plane and go to Newcastle, or wherever. The family support, peer support, is very, very important while your child is going through the stage of going through surgery. It is a very important point that you have raised.

WA: And it is one that has been raised by everyone that has come along. [redacted] is at the back and wants to say something.

P8: I am [redacted] and this is the rowdy [redacted], and I am sure you think it is highly inappropriate to have a child out at this time of night [WA: Certainly not!] but that is how important this meeting is to me. All I want to say is that it is not a question of such, it is more or less a plea. You have talked tonight that numbers are not a factor, but the subject has come up a few times, and what I would say is that we are not a statistic. These children have names and faces. You walk into Clark Clinic and look at the faces on the wall of the many children that have been helped. I would like you to think with your heart and not with your head. These are our babies and they are real people, not numbers.

WA: [redacted], while you are there, might you be able to say about this, because someone last week raised the point of children who had multiple needs. And who therefore don't just go to Clark Clinic because of their cardiac needs. They maybe have other aspects that they need help with too, and then it is all a one stop shop effectively.

P8: Absolutely, when I had my 20 week scan [redacted] heart defect was picked up. [redacted] had an [redacted]. Immediately all my care was transferred from [redacted] to the Royal. All my antenatal appointments were taken there, the care was second to none. When I was given the news, they said that there was an [redacted] as well. So dealing with the heart defect, and then the other blow. I then thought, I don't mind about the heart as they can fix that. We were then put in touch with Nurse [redacted] who is the liaison nurse. [redacted] would just ring me up, and I would cry on the phone, [redacted] was such a support and [redacted] was with me the whole way through, she took us round Clark Clinic and explained everything that was going to happen. [redacted] introduced us to the staff. I can't thank [redacted] enough for what [redacted] did and I was lucky and it was picked up. In hindsight I was prepared for what was going to come, because it was picked up so early and I was very, very fortunate, so it had given me the time to prepare myself as I was informed of everything along the way, then when it came to it we actually thought [redacted] was going to have [redacted] surgery straight away. [redacted] was born in the Royal, and the care was so good, and the people were so supportive because with [redacted] having [redacted] I needed the extra support. They were so caring. [redacted] went on until [redacted] and it was decided then that [redacted] would have [redacted] surgery so [redacted] kept so well up until then. And I had no fear about going to the Royal and handing [redacted] over, because I knew [redacted] was in good hands and I knew everybody there. [redacted] is the light of our lives and [redacted] wouldn't be here today, and I want to thank the staff up

there, because nobody understands. I said that we never thought that it would come into our lives that it would come to our door. There are people who probably think that this won't affect them, that it is not relevant. Until it actually comes, this is why we are all so emotional. These are our babies. They are the most precious gifts that you can ever be given, and we just want the best.

FC: To listen to someone like [redacted] is humbling for any of us, because parents are always much more eloquent, and can tell the story because they live through it and I want to congratulate you on how well you have spoken, not because you have said good things about Clark Clinic, but because I think the message that you have and the struggle that you have come through with [redacted], and thankfully [redacted] has come through the other side of it. You story illustrates the complexity of what we are dealing with. In NI we have many good things about the service and because of a population that is 1.8 million it means that in this new era of cardiac surgical care, where the move is to big units, then we face this terrible dilemma. What we want to do is to try and deliver what we have delivered in the past in an environment where there are many pressures for us to do things differently, or for that service to be delivered in a different way. I hope that through this process, we all come to it with different views – we have to find what can preserve what you have been through and yet secure safe surgery for all of the children that come after [redacted] in the years to come. I hope that we can do that. There is no doubt that we will have difficulty in the next two to three months in trying to come to some kind of consensus that we can agree to but we will have to.

P9: I'd just like to ask the panel, if it was to move to GB, and not stay in Belfast and Dublin, would it be air travel? And the air travel, what happens in bad weather, ash cloud, would they be able to travel. If it was an emergency how would they get that child to GB?

WA: Thanks - and on that basis, too when we look at the criteria, which are on the next page. Ensuring emergency and urgent procedures are undertaken within clinically indicated timescales, which I assume means as quickly as possible if that's what required. How do you deal with that Dean?

DS: This is the short answer to your first question, if the service is provided within GB then it would be air travel. As I am sure some of the parents within the room have used scheduled airlines where it is a non-urgent or non-emergency case, in an emergency situation through an appropriate air ambulance arrangement. Although it is something that sets NI apart from other parts of the UK – we have a stretch of water between us and the rest of the UK and that does prevent challenges. In terms of comments that have been made by colleagues on the working group about how the working group has worked in practice – this has been one of the key issues that have been flagged up by working group members. From a clinical perspective, the practical challenges of being able to respond to emergency situations within the clinically indicated timescale when there is air travel involved, and also on the softer,

less clinical side of things, and some of the points that have been made tonight, some of the practical difficulties associated with air travel across the water in terms of whether it is as straight forward, and the points that Irwin makes about the ability to simply to get in a car and visit a family member or some of the other practical difficulties about family members being separated, especially the family there when you were across the water for as long as you were with your child. These are all very real issues. Bringing it back to what we are here about tonight, we have sought as a working group as far as possible to capture these issues. The issue of emergency access is right up there as the second most important criteria in after the safety and sustainability one. As we have said in other public meetings, that came up the pecking order. It wasn't there, that high up at the start, but through discussions with Frank, Rosie and other clinicians, with parents and others, the view around the table was that actually it really was a very important issue and we needed to ensure that we gave it consideration, and it is now right up there at or near the top of the list in terms of how an option might score.

WA: When you look at that next page, those weightings. If you take that "ensuring emergency procedures are undertaken within clinically indicated timescales" and add it on to ensuring services are accessible, because that applies to the same thing, doesn't it? Then you have got something which is as important as what's down as the most important element.

DS: There are lots of different angles on accessibility. Just that everyone in the rooms understands what we are trying to get at with the different criteria, criterion two is simply around in an emergency situation, does the option facilitate appropriate clinical intervention within the clinically indicated timescale? Option four is more around the geographical accessibility side of things. It is more difficult to be in Dublin than it is in Belfast, it is more difficult again to be in Birmingham or London, than it is in Dublin and so on. Someone in the room mentioned the waiting time as well. Which is the other angle on the criterion for there, which is does the option ensure timely access; patients and children wouldn't have to wait too long for treatment across the water. Certainly, it is all in the same space that we are trying to address those and we would be very interested to understand if we have identified within this document all of the relevant things to think about when comparing different options, and secondly if we have identified all of the relevant thing to think about, have we got their relative importance right.

P9: Surely by this time, there must be a plan put in place for this air travel, and surely it is safer to stay in Belfast or Dublin and all island, but I think it is only a matter of time before a child loses its life. If that child needs an emergency operation it is just a matter of time, who is going to pay the price then?

WA: What about those criteria? Are there things that are there that don't look as important as you would like them to be? Or are there other elements that you think ought to be there? [redacted] has [redacted] hand up.

P1: Just following on from what [redacted] is saying, and I don't think it has been answered. Who is going to pay that price? Ultimately it is the child's life. I have been concerned on a number of occasions, I have been to the working group meetings and I have listened to Dr McCarthy on the radio and in answer to question about these children who require surgery, within a number of hours in an emergency situation, she has repeatedly stated that those children are a minority group – there aren't that many of them. Do you accept, Dr McCarthy, that that appears to us as parents, that you are minimising that group of children? Surely one child's life at risk is too many. Whether or not that is a small group or a large group, to us as parents is irrelevant. I would like you to answer that. And finally, I would like to say in relation to these criteria weightings, are we to assume that the working group are to have a mutual agreement on all of this, and what happens if they don't? Who makes the call then?

WA: Miriam, let me put the first part of that to you.

MMcC: There are a couple of bits that I would be happy to answer. Firstly in terms of whether it is one child, I absolutely believe wholeheartedly that every child is really important. As any mother, we all worry when the slightest thing is wrong with our children. We worry more if there is something significant. I absolutely believe that every single child is vitally important. If I have said it is a small number affected, that is a fact. That doesn't mean that that small number doesn't need a lot of time and attention to be sure that we have the right care for them. And in the working group we have spent actually many hours just talking about the emergencies and the very fact, and we have said in the working group and I have said it myself in the working group, the very fact that it is a small group and small number mean that it is more important to have resilient plans in place, because sometimes you can cope with emergencies if they happen every day, if it is only once a month, people are less well versed in how to deal with emergencies. That is something that we have talked about a lot and that we are all committed to. Everybody in the working group whatever their perspective, they are committed to that. Just a couple of things that we do need to remember – already, a proportion of our children do travel to other places and they tend to be the children who need the expertise and are more complex, and [redacted] and [redacted] have talked about going to Birmingham. None of us would envy [redacted] months in any hospital away from home, but there are a number of children who need to travel to get that real expertise. Already there are a number of cases, as I am sure that you will know from your own experiences, where children need to travel urgently or in an emergency, because we may not have the facility or the ability to do surgery on that day in Belfast, and there are very robust arrangements, and Frank and his colleagues work day and daily to ensure that children are as well prepared for that travel as possible. Although we accept that sometimes it is only hours or days after birth. We are doing a separate but parallel piece of work looking at air transport, and in particular looking at emergency air transport. That will probably be brought back to the working group sometime early in

the New Year. It is a separate piece of working, looking at how well our transport service functions at the minute, and what if anything is needed to improve and develop it. We are not aware of any safety issues with the transport service. We have had no reports of any difficulties, but we recognise weather and other things that are beyond control means that it is inherently a more tricky way to travel but it works well – Frank, I don't know what your view would be, but it seems from the reports that we get, it works well for those children who need it. Although we are also conscious of a very practical issue and that is sometimes when children travel by air, the ambulance is so small that a parent is unable to travel with them. And I know that must break peoples' hearts, and it would break mine if I was in that position. Yes, it is a small number, but that particular issue of making sure emergency treatment is available, has taken up a huge amount of time in the working group, and I hope will take up more time, because it is an area that we need to address. One other issue is what will happen if the working group don't agree, as Frank quite candidly and truthfully said, we don't agree and one of the benefits of the group is that we have different perspectives and collectively that brings us to a better place because we hear from everybody and a variety of views. We do need to knuckle down early in the New Year and determine as a group what the best way forward is, and we would aim to be determining that as a group. And that means healthy discussions, debate, arguments, whatever it is that is needed to get the best solution. The one thing that I think that everybody in the group is at one on is that everyone wants the best solution. And we need to work through that. We will certainly have our work cut out for us, but this is something too important and we need to do it well.

P10: Could I just say in response to that, Doctor, I also heard you on the radio defending this way of going about things, and as [redacted] said, I know and these people here know what you meant by that. I don't know about the rest of the people on this panel, [redacted]. Because I know which side you are on in this debate.

WA: I think that is a bit unfair if I might say so. We need to treat each other with respect here tonight and Dr McCarthy is giving you her honest answer and you can make your own mind up.

If no one else has anything else to say, we will leave it at that then. This is the first time Frank that we have had the chance to hear from you, would you like to say something as we are wrapping up?

FC: It is my first experience of being on the panel. I think that this kind of meeting is crucially important so that people do get to express their views. From the start of this process, to where we are now, everybody has a much better understanding of the complexity of the issue. That is most helpful, and the most powerful voice is the voice of parents. As Miriam said, we all do come to this group with different views and I, as a clinician, have strong views as to what I see as the way forward and I will

put those in the submission, and although we have had our differences in this group, I do have to say that I do whole heartedly trust the people who are within the working group do want to see the best outcome for all of the children. We may have different views, but we do have to respect that everybody comes to this with a genuine wish to do what's best for the children. Sometimes, I like you as parents, I get angry at some of the things that I see might happen. We have to get what's best – and sometimes that will involve difficult decisions but I can assure you as the clinician on the group, and as all of the people who are here, and Sarah Quinlan is here as the Executive Office of the Children's Heartbeat Trust will represent your views as well. At the end of this process, I will not be signing up to something that is not in the best interests of the children. But I do respect the views of everybody else that they have to bring their concerns and view to that as well.

WA: Could I just ask too, Miriam said that there would be robust discussion and many more meetings as you worked your way towards resolving this, Dean – I am assuming that the outcome of this consultation will greatly inform those robust discussions?

DS: Very straightforwardly, when I look at the journeys, Irwin was telling me tonight, he and [redacted] had a four hour drive up to Derry this evening – Miriam referred to busy things that parents have, I got a phone call from my wife about a [redacted] tonight, and who was doing what, the reality is I am sure everyone would have better places to be tonight, as if this was all some show. We are all here because we want to hear views. I can absolutely assure you that if the work of the working group to date has proved anything, it is that we do this, and I know [redacted] has been at some of the meetings in an observer capacity and you would all be very welcome to come along to observe (maybe not all at once without a bit of prior notice) but you would all be very welcome along to that. We are trying to be as open and facilitative as possible. We will listen to views expressed through this process and with the likes of my colleagues beside me on the panel, who are on the working group, and others, we will I assure you ensure that appropriate consideration is given to those views. In terms of in the first instance, making recommendations to the Minister around the framework for his decision and then once he is confirmed or otherwise that he is happy with that framework, then applying that framework to come up with the best option for NI looking ahead and taking account of all of the issues that we have heard. Certainly the views tonight will have been and will be listened to carefully. Anything you say to us in writing or through other media after tonight will be listened to carefully and we will seek to do our best to reflect all of that in the document that in due course goes to the Minister.

WA: Just a final comment – yes:

P11: My name is [redacted], an interested party. I am just thinking, when Mr Poots makes his decision next spring, is that it? Maybe it is a political question, if there is

disagreement in Stormont, can it be stopped there, or if Westminster rejects it can it be stopped?

WA: It's his decision, isn't it? Judicial review, isn't that what always happens here!

DS: It is certainly not a Westminster decision, it is a local one.

WA: It is a devolved matter so it doesn't go to Westminster.

P2: Can you tell us what you think would be the best option – in your eyes what you think would be the best option?

DS: I am not a clinician as I said earlier on tonight. I genuinely don't know at this time. What I do know is, and I know better now, the huge complexities that are around all of this in terms of the emergency / non-emergency issue; the linkages between the surgical service and the cardiology service; the issues for children with more complex needs; the wider issues around all of that. But I also know the issues that are made clear within the independent review by Sir Ian Kennedy, which is flagging up sustainability issues for the service. So, I don't know but I have a better understanding of the things that I need to think about in the job that I have and in chairing the working group, and things that we as a working group need to think about. But I genuinely don't have a clear view of what the answer is. I would like to see a service that is safe and sustainable and as accessible as possible.

P2: But where would you like that service to be?

DS: I would like that service to be as close to people's homes that can be safely and sustainably provided. What that turns out to be, I honestly don't know.

WA: On that point, I will wrap it for tonight. [Can the panel not answer that question?] Well, it is not what we are after, but if the panel want to give their views?

IMcK: You heard it before, keep it in this island for me.

P2: As parents we all agree that is should be an all island. We would go anywhere for surgery for our children but to keep it as close to home if we can, if we don't need to go across the water for minor surgeries etc if we can keep it here, then why can't we keep it here.

IMcK: That's what I say. An all island thing here, and obviously there will be forever and a day possibly complex cases have to go across the water but that should be an exception rather than the norm.

P2: But if it is not a complex and it can be done here, why put families out to go the whole way and separate them from their other children. We spent [redacted] in Clark Clinic. It was only an hour and a half drive, but we had to leave [redacted] children at home for [redacted] months with grandparents. He had to take [redacted] months off work. If you

have to go across the water for [redacted] months, it is just not acceptable, if it can be done here. If there surgery can be done here.

IMcK: Being no disrespect to you, but you are preaching to the converted here.

WA: Frank?

FC: What I want to say, is what I want to see for the patients that I look after is to have as much of their care delivered as close to home as possible. I need to be sure that there are structures that can provide that as safely as possible. I would like the minimum number of children to have to go away, anywhere for their treatment and that means that we have to change the way things are now in terms of providing much better structures to support what we can deliver in Belfast and recognise that a small number of children will have to go perhaps still to Birmingham. In many ways the logical pathway is building structures with Dublin – we have to be sure that all of the services provided across Belfast and Dublin do provide the best outcome and we have to have assurances on that. There should be a model that we can work that not many children would have to leave the island of Ireland.

WA: Rosie, can you see that model as well?

RB: I agree with Frank. I see my role on the group as being as impartial as possible – I work in the Belfast Trust, I have always worked in the Royal, I am a cardiology nurse by background. But I am really trying very hard to divorce the emotion of that and all the time that I have invested in Belfast in that to be as informed as possible about all of the different options. And I think the diversity of the people around the working group – every time we go, we are always hearing something different, we are always hearing something that we hadn't thought about and the same for these groups. I don't have a preferred option in my mind; I am trying to be as impartial as possible about them all to make sure that any conversation that I have with the working group or in correspondence after it is as informed as possible and to look at all the nuances and the importance of everything.

WA: Finally, Miriam, there seems to be view that minds have been made up. Is that the case?

MMcC: Well, I certainly don't have a fixed view of the future. I have led for a number of years in a previous role, the work that has explored the relationship with Dublin. I have seen in that a huge potential. I have also seen really difficult areas and challenges, and we have worked through that over a number of years. We tend to say that we want to have things as local as possible and as specialised as possible. What I would like to see is as much provided locally, and that includes all the cardiology that we can provide locally but we specialise where specialism is needed. That's what Frank is saying, that we do as much as we can close to home and we procure services for specialist services but I think it is really important as a member of that working group to not have a fixed view. I have learned a huge amount since

joining the working group and with every day as Rosie has said, we learn something more. Therefore our views evolve and I would anticipate they would evolve even more after the end of the consultation. That's why this is important, not that we have fixed views on the way forward but that our views are informed by what we hear tonight and on the other occasions where we listen to you, the users of services.

WA: Thanks to everyone for coming.