Paediatric Congenital Cardiac Services Consultation

Public Meeting 19 November 2012

Killyhevlin Hotel, Enniskillen

Panel members:

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

WA: We are going to start off with service specification which we talked about – the ideal service for children in NI with safety and quality; with good outcomes; access; clinical engagement; the arrangement for parents and what we would like to do now is to hear from you, and your views on that. Please introduce yourself if you would like to and wait for the microphones. Our first contributor:

P1: Just before we go any further, I would like to clear something up, because I am a bit confused. If this surgery is removed out of Belfast, is that intervention included, is that any child needing any cath? Did you include those numbers in your figures that we are talking about here? Is it included?

MMcC: The clinical advice is that if a unit is undertaking interventional cardiology, that they can only do so where there is surgery available on site. That is because if there are complications during the interventional procedure, you need to be able to turn around, bring a surgeon in to do the operation that the child may require immediately. If there isn't a surgical presence on site, it would be expected across all of the UK that interventional cardiology would not be done, on any site, without that surgical cover.

P1: So, are they included in that figure? If that's not going to be the case, if that intervention can't occur, if God forbid it was to be removed from Belfast, were those figures included?

MMcC: The figures are in the consultation document, and what we would anticipate is that we need surgery for about 110 children given that about 30 are travelling at the minute to other places, and some will continue to travel no matter what the arrangements are. And up to 50 interventional cardiology procedures. Both numbers are in there.

P2: Just on that note with the intervention. I currently have [redacted] children, [redacted] of which have complex congenital heart disease and my [redacted] if [redacted] hadn't had the, [redacted] was very, very sick when [redacted] was only [redacted] old and had to have emergency

[redacted]– if this surgery was taken away, [redacted] wouldn't have that cover, so therefore because the numbers are small [redacted] would just be left to die?

MMcC: We recognise that there are a number of children who require interventional cardiology procedures as emergencies, and Dr Frank Casey, who I am sure is familiar to some of you, hoped to be with you tonight because he is much better at explaining those clinical situations

P2: It was actually Dr [redacted] who saved [redacted] life and I am very familiar with [redacted].

MMcC: Part of the reason why he is not here tonight, is that he is in Belfast delivering that care to other babies.

P2: Absolutely, which he should be doing and continuing to do.

MMcC: The reason why we have as one of the issues in the service specification and in the criteria, the need to respond to those emergencies is for exactly that kind of scenario. We know that babies, when they are a few days old and are in need of emergency procedures, need them quickly. We are very conscious of that, so recognise that and I hope your children have [redacted] done well following their surgeries or interventions?

P2: We had a rocky road. We have a fantastic team here.

McMcC: That team, Dr Casey and his colleagues and the nursing support will continue to be there because that is absolutely fundamental…

P2: But can I just say on that note – the sustainability for this review to keep up the skills of the surgeons. If this is all taken away, that is going to have a knock on effect on the consultants and all the other clinicians in Clark Clinic. They are not going to be there forever. They are going to retire, which happened to [redacted], and if they retire who is going to want to come over, as a cardiologist and not be able to practice these skills. You are saying that it is not going to be affected. Further down the line as a knock-on effect, it will be affected.

DS: Those points are well made, and were made by a number of the members of the working group and are reflected in the consultation paper. So in thinking about the different options for the way forward, certainly Frank would have made the point strongly exactly that the interactions and interconnections between the recruitment and retention of staff issues, and so on. It is an important issue, but our view is that they are adequately reflected within the consultation paper. But it is a valid point that you make.

P2: But in the consultation, does it not say that it will remain but it doesn't highlight the fact that it may not remain further down the line? These children are sick children. They may look healthy on the outside, but these are sick children who are

going to need constant care. Further down the line – whether they get a sniffle or a cold, we need this expertise to remain here.

DS: All of those points are valid points, the challenge for us within the consultation process and what we sought to do as Miriam said in her presentation, you know better than we do, it is a complex area that we are describing here. We have sought to communicate it as straight forward as possible and Miriam has sought to do that tonight, but even so, it is still a complex area. The focus for us is to try and help in developing a framework that allows us in the first instance to make a recommendation to the minister in due course as to what a framework might look like for assessing the different options. And through the working group, that the various parents and parent group representatives are on, to make a recommendation to the minister. The challenge for us is to make sure – exactly the points that you are making tonight, are very relevant, to make sure that we haven't missed something, an option that might be relevant; we haven't missed some interdependency that might be relevant, so that we have all of the facts on the table. There is any number of things, pulling in different directions, emergency surgery, emergency interventional cath type procedures; more elective routine work; the ability to recruit cardiologists, and so on, and all pulling in different ways. Why we are so keen to hear from you all tonight is to either reassure us that we have captured most of the main points – I would be surprised if we have not withstanding the strong input of the working group members, I would be surprised if we capture everything, and we are keen to hear views and different perspectives from the audience.

WA: Irwyn, it would be interesting to hear from you on this. You have been involved in this working group and in developing the questions that are being asked. What have you and the other parents been saying around the points that [redacted] has been making about [redacted] children.

IMcK: This was a big concern for all parents, of having to move for any reason out of Belfast. We have had quite a few families that have had to go – we have had 13 procedures for interventional cardiology, which to me was rather surprising, had to go to GB this year. It is a concern and it is something that they would rather take place in Belfast. In the basic run of things, of heart operations, it is slightly down the scale of the more complex cases, and there is a strong feeling that they should stay, but it is trying to find the arrangements necessary.

WA: Can you understand what Miriam was saying that it is not normally done unless there is someone standing by who can step in?

IMcK: That has always been the case – and it was always recognised that there has to be a surgeon sitting outside the door reading the paper while it goes on in case there is a problem. Most parents recognise this.

P3: My name is [redacted], my [redacted] is a cardiac patient, [redacted] is only [redacted], and has had [redacted] operations to date. All in Birmingham because of the complexity of the

condition. I understand as a parent what it is like to be told that you have to go to Birmingham to get treatment, and it is very, very difficult to leave family and friends over here. They are reliant on the odd text to see how things are going. It is very hard as a family to cope in that situation. But you have to. My concern would be, if [redacted] (my [redacted]) – we live in [redacted], we are quite a bit away from Belfast as it is – if [redacted] needed an intervention procedure to get him to Birmingham, if you take this out of Belfast, [redacted] is not going to get that. I get the feeling that [redacted] is just a number. But [redacted] is my [redacted] and [redacted] deserves more than that.

WA: Is [redacted] doing ok at the minute? Good. Next comment please.

P4: At the end of last week, it has been brought to my knowledge that in Birmingham, they have ceased taking patients from NI. How is that going to, is that not true?

DS: No, that is not true.

P4: I was at a meeting at the end of September that was organised by the Children's Heartbeat Trust and I signed up to receive information from them and I have received that information from Children's Heartbeat Trust.

P5: I am Sarah from the Children's Heartbeat Trust. It was that Birmingham don't have the capacity to take all our work, whereas that was initially being considered as one of the main options, because we do enjoy a very strong relationship with the consultants over there. It is that they have returned to say that they would not be able to take any more of our surgery, but the very complex cases that do go there, will still be going there. To the best of my knowledge.

P4: It is another thorn in my side if they were going to stop surgery altogether from NI. In Miriam's presentation, she said that the diagnostic procedures would still remain in Belfast. Is that correct?

MMcC: That is the current plan – we are not consulting on that.

P4: But sure part of the diagnostic procedures are things like catheterisations?

MMcC: There are two different kinds of catheterisation. One is where they are doing the catheterisation and putting in the dye in order to identify and diagnose the problem, and the other is where they are doing the catheterisation with the intention of doing the procedure which is therapeutic, closing the small hole in the heart or whatever. The diagnostic ones can continue, they don't need surgical cover – it is the ones where they are intervening, and my understanding is that something happens when they are in doing the intervention, and some little bit drops off the end of the catheter and then they need surgery.

RB: There is diagnostic cardiology in the cath lab which is just purely cardiac catheterisation to either diagnose a heart condition or check on a previous surgery

that has been done. Then there is diagnostic with intervention, whereby they go ahead and have a formal treatment.

WA: I will come back to you, but we have a gentleman at the back

P5: I am Raymond Farrell, one of the councillors here in Fermanagh District Council. This is something that I have taken a keen interest in, and I have made it my business to speak to parents and to people who have been impacted and will be impacted by this. I think that all of us want to see a service of excellence, a safe service, a quality service, and I think we all sing from the same hymn sheet. I commend this. My difficulty is – and I want to pay tribute to the Clark Clinic for the excellent work that they do, and the staff, and that needs to be noted – we are looking at like for like in this. We have a situation where this report has been drawn up in my understanding to accommodate and acknowledge some 60 million people in England and Wales. And it is not treating like for like. I feel the people of NI have not been given a fair deal on this one. Quite simply because the process of consultation which was afforded to consultants in England, not afforded to the consultants in NI; parents in England and Wales were given something around two years to give their views and opinions in this matter, and my understanding is that in NI, parents were given around an hour. On that basis, I feel we are not getting equity. I think that is important that this is pointed out. It is also important to say that there was consultation and a report done in Scotland where it was recommended that the Royal College in Glasgow hospital would see to accommodate 400 patients and four consultants. I believe that has not been met in relation to patient number and staff, but still Scotland is being allowed to continue on the service it provides, which is interesting.

In relation to the point of access to service, I am concerned about this issue in relation to flying. The report itself stated that it is not a viable option. Why should the people of NI have to be considered in the light of this? A sick innocent child is not able to speak, to say the pain that it is going through, to ask questions, to point out where it needs help. We have got to look at this in a very sensitive and very unique situation. I am most keen and will do all in my power; I have spoken to the health committee at Stormont on this, and to be fair to Jim Wells, he has acknowledged the concerns. I believe Edwin Poots is acknowledging the ground swell of concern there is on this. If it is good enough for the people of South Wales, and Cornwall to be allowed to keep the centre open in Bristol because they are outside of a three hour emergency travel time, it is good enough for the people of NI to have a service maintained in our province, in some cases with the support of services in Dublin. I am not against things in Birmingham, because there are occasions and times when we need to use the expertise there, but where possible, we must seek to maintain a service on the island of Ireland and that has got to be our priority here tonight. That is the message I want you to take home with you tonight. I think it horrendous that a sick child may have to use a commercial flight to get surgery in Birmingham, to expect that child to go to the International Airport, full

of people who may be unwell themselves, and leaving it open to vulnerability of further infection. To me that is unacceptable, and we need to catch ourselves on, look at this seriously, sensitively, and maturely. I would ask you to really consider the views of the people of rural Fermanagh tonight, who are very grateful for what we have received in Belfast. It is a two hour trek for people here at least. All of us have had sick children, some of us have had even more traumatic experiences, with our children. We need to think about this seriously. I acknowledge your professionalism, and your expertise, but I ask you to acknowledge the people's feelings and most of all a child who cannot explain its pain.

WA: DS, is there a level playing field as far as the UK is concerned? This safety, and quality and sustainability is being measured very much on the basis of what is the standard – is Raymond right when he says it is not a level playing field?

DS: Raymond made a number of important points. It is easy to wander into a place with discussions tonight or when reading the consultation paper and assume that there is something written in stone here. We have set out here what we have worked up with the other members of the working group including parents, the ideal service specification for the ideal service. That is as documented here. And one element of what an ideal service looks like is the safety and quality element, based on the advice of professionals across the UK, is that outcomes are best when a unit is seeing 400 (ideally 500) patients a year, when a unit has 24/7 cover and so on. That is what is recommended as professional practice. We have reflected large chunks of that UK best practice within this document, after discussion with the working group members, but it is for consultation. It is very important that we understand that. It is reflected here within the document, reasonably accessibly, but it is for you to comment on. If someone had a view in a room that it wasn't important to have 24/7 cardiac surgery cover with all of the risks that would be associated with that, when there is an emergency… you can't have half a service – you either have the service or you don't – then that is clearly within your gift to flag that up. There are challenges with the number of doctors we have and the services we are providing in terms of maintaining the sort of cover that we wish to maintain, and those challenges will only get greater. The key point is that it is a service specification. The working group's view, the Minister's and Health Board's view of what is an ideal service but it is for consultation. If there are different views within the room tonight, or through other parts of the consultation, then we are very keen to hear that. The blindingly obvious difference here in NI that was alluded to is the big bit of water between here and the rest of the UK. That point is very well made, particularly where time is more of the essence.

One other point regarding the scheduled airlines point, the vast majority of children that need paediatric cardiac surgery are non-urgent patients. The lady whose [redacted] was seen across the water – I assume some of those journeys were made on scheduled airlines. But not directly relevant to the consultation, but in terms of the value that the working group has been to us….

[It is relevant to me.]

A number of the parents on the working group have made just that point. So whilst it is not directly relevant to the consultation, there is a focus group being organised for parents related to, but not part of the consultation process, precisely to tease out some of those very real issues, for parents in terms of the practicalities. It has become apparent to us that there are some very real issues that in any service model we would wish to address.

WA: Next point,

P6: Just on the point that [redacted] made. My name is [redacted]. It is to do with coming from Fermanagh and this three hours access to services. In the mainland, they have that service within three hours. If this is taken from Belfast, I can't see how in an emergency situation here in Fermanagh, that a child would have access to surgery within three hours. In the consultation, retrieval teams should be at the centre within three hours. Is that being seriously looked at in this consultation for all children? That three hour time, when you are from this end of the country is a very important issue.

WA: Can I take the point from the lady behind you?

P7: I would love to hear the panel's view on the actual review itself. I am sure everybody is aware in this room that the review is actually being reviewed by Parliament in England. The flaws that they have in their review, than what we have in our review, are a lot more flaws. What is your view on the review being reviewed by Parliament? We are sitting here debating this, but the review itself is actually being investigated by Parliament. Surely that just shows how ludicrous this is, and they don't have to travel across the water to get to the surgery within three hours. I think that it is ludicrous that we are even having this conversation.

MMcC: Just to clarify, there are a number of different things that we can touch on this evening, but just to deal with that review that is on-going in England. The safe and sustainable standards were developed a few years ago. And they were developed with an eye to defining what was considered high quality care for every child needing surgery. They were developed with professional groups and with parent organisations, and Irwyn, your organisation was represented in that. Those are standards that are signed up to by professional bodies across the UK. Those standards were then applied to units across GB and there were visits to every unit. Then reports were issued to every unit about the extent to which they met the standards or not. Another piece of work came along which was geared towards deciding what the configuration of those units in GB may look like, and specifically was around England. There are no paediatric surgical units in Wales, children either travel to Bristol or travel to Liverpool. The work that was done by the Joint Committee of Primary Care Trusts (JCPCT) said that in order to meet the standards of having the right number of procedures, and 24/7 care, and the right number of

consultants, we should have not 10 units in England, but seven. Because if we have seven units, they will all be a bit bigger, and actually all the evidence is that the more people do the better the outcomes. The more operations a surgeon does, the better the children do.

I think it is really important to understand what is going on at the minute. This is a very complex area. The JCPCT made an announcement on the 4th July this year that they will move from 10 to seven units. Three units they said would close, one in London, the Royal Brompton, one in Leicester, and one in Leeds. There were then challenges brought against that decision by two if not three of the units that were listed as units to close. It is that decision to move from 10 to seven, and which seven will be the ones supplying care across England that is challenged at the minute. And it is that decision that is now being reviewed by an independent panel. Is it the right thing to move from 10 to seven, and if so, which seven? Or should we be moving from 10 to six or eight units? There is no challenge about the standards. The standards are the standards agreed by professional bodies and parent groups. There is a challenge going on about whether Leicester and / or Leeds and Royal Brompton should be the units to close. That is the limitation of that review that is being carried on in England at the minute due to be complete at the end of February.

WA: You are shaking your head, but I am guessing that is probably correct?

P7: This panel, with Sir Ian Kennedy and the experts found Bristol to be one to be found safe. By this panel of experts, this hospital was found to be safe. No less than two weeks ago it was given a warning by the health watchdog. We are taking on board what these experts are suggesting. But it has been proven that their suggestion isn't working. Bristol has been given a warning two weeks ago. Why are we letting them anywhere near the children of NI?

WA: That sounds like a reasonable concern. If a question mark is being raised over a hospital that is said to be fine, you can see why as a parent you would be worried about that.

MMcC: You are absolutely right. Sir Ian Kennedy and his team deemed that to be a unit that met the standards, and you are right that there was a warning from the Quality Commission and they have reduced the number of beds, and they have reduced their activity in order to ensure that they provide better quality. You could argue that it is indicative of the scrutiny that goes into units that provide paediatric surgery and that step from the CQC will help ensure that standard is brought up. None the less, Sir Ian Kennedy and his team cannot anticipate what will happen in any unit if staffing changes in the future. They were in Belfast for two days. They met with staff, with parents. They had two separate meetings with parent groups. They took on board what they heard and they provided what is a fairly candid report on what services in Belfast are like. They did conclude that there were many excellent features, but our activity of such a small number means that we will always

have potential risks in services, and that's what they said we ought to be addressing. That is the reality of the activity.

WA: Thanks for all of your points on that particular aspect. I am keen to move on to the second part of the consultation, I do want to try to stick to the 20 minutes for each, and there will be a bit of wrap up time at the end. The second part of this is the options for the future provision of the paediatric cardiac surgery and interventional cardiology. Six different options on the screen behind me, and I would be interested to hear your views.

P8: Surely it would be on the Trust to save money by keeping someone here to do the operations, instead of money coming out of the Trust to pay for flights to go across to GB.

DS: The issue remains that there is simply not enough volume of activity within NI to keep a full team of surgeons busy which is the difficulty. Within the criteria, we have flagged up that this is not a resources issue. Resources are right at the bottom of the pile, in terms of the importance that it has. It has to be reflected as always, but I don't regard resources as being the centre of this discussion. The discussion is primarily around safety and quality and we can't put the numbers through that would support the size of the team to deliver the model you are describing.

P8: But say your child had to have an operation in Belfast, and someone came up from Dublin to do it, and that consultant went back to Dublin, and there was no one up here to help the child if it took ill again? What would be done then?

IMcK: That's one of the problems at the minute that we don't have 24/7 cover.

WA: You have experience of this in your own family haven't you?

P8: Yes, what would happen, would that child just die if there was no one there to save them?

IMcK: That's what we have identified as one of the big problems at the moment, and it is one of the things that we will be working towards, 24/7 cover. And with the amount of surgeries performed every year, we haven't got the staffing there to look for 24/7 cover unfortunately.

P9: Just on that point, surely it is easier getting a consultant back from Dublin than it is getting a child over to Birmingham again after surgery if they need follow up care?

IMcK: For immediate 24/7 cover if you have an operation today, the surgeon isn't there. When [redacted] was about, he was once brought from a boat off [redacted] to get to the Royal in time. He was on call 24 hours a day, and then with the locality he lived at, he could be there in a very quick time. The concern I have from other parents is that to get someone from Dublin on Thursday to get to Belfast in time you might be too late and this is after an operation.

P9: I still maintain here tonight that if the surgery in Belfast is going to go, we need an all Ireland approach to this, because it is…

WA: When we look at what we have got on the screen here.

P9: Sorry, Sir Ian Kennedy's report does not favour that all Ireland approach. That's what has been happening down through the years, that is mostly shared with Dublin. There is nothing on paper between the two governments and he is finding that a flaw. And that is why he is favouring Birmingham more.

MMcC: In fairness, he did in his report raise reservations about the Belfast Dublin model, as currently operating. So what we do at the moment is some procedures in Belfast, sometimes the surgeons are coming up and that is really good in terms of getting that professional collaboration. But it still means that they have to leave again and go back down to Dublin. It still means that we have a very isolated, vulnerable unit when they go. As Irwyn has said, if something happens late on a Thursday night, there may not be someone available in Belfast, the surgeon in Dublin may be available, but their first commitment will be to the children in the Dublin hospital. So what he was expressing reservation about was having a model that had surgeons in both places. But the teams were too small in each place. And what he was advising was that it is a commissioning decision, it is for NI and the board and agency to set out what the options are, and hence the reason why we have included options which include Dublin, Dublin and Belfast, Dublin Belfast and GB etc.

P9: It would be a concern of mine, if my [redacted] had to go to Birmingham [redacted] is not going to be able to be kept there until [redacted] is discharged home. I would be looking at you are going to be transferred back to the Royal to Clark Clinic before you get home. Maybe a day after surgery or something. To me, if [redacted] needed care again straight away [redacted] would have to go back to Birmingham if Dublin isn't involved in some way.

WA: To look at these options, the questions at the bottom are interesting. Are the options for future service provision appropriate? Are there other options which should be considered? Yes, [redacted]:

P10: I would like to ask Irwyn. Which option would you like to go for here?

IMcK: Funny you should ask, I have been from 2007 when [redacted] intimated that he wanted to retire, I said then meeting the Public Health Committee that Belfast-Dublin was my preferred option. And I have seen nothing anywhere to change that. From a personal point of view, I would be quite happy to walk out this door tonight with this option.

P11: My name is [redacted]. My [redacted] had surgery [redacted]. The wee [redacted] that was in having surgery with [redacted], we had been in Clark Clinic together for [redacted] prior to having surgery. Thankfully my wee [redacted] surgery went ok. [redacted]

[redacted]

P12: It has been said the Prof Ian Kennedy spent two days in Belfast when he was over doing this. I think that is the problem. Maybe if he had have come up to Fermanagh to see the difficulty we have to travel to Belfast, never mind flying to Birmingham. Maybe he would have a better understanding of things. On the first page that was shown tonight, as far as I was concerned it was a glowing report on the unit in Belfast. And then it went on to the second page it said that there was some safety concerns.

WA: Sustainability concerns

P12: Yes, sustainability to me is a code word for financially sustainable. That's the bottom line. The unit in Belfast, the way that it is working between it and Dublin, I hear no people criticising the way it has been working. But it is sustainability, financial sustainability that it is all about.

DS: As I have said already, this is not about resources. Not about financial sustainability. I would suggest that the cheapest option on that list is to continue to provide services in Belfast, any other options would cost more because of the need to maintain services in different locations, and to pay for services in different ways. So it is not about financial sustainability. It is about service sustainability.

P07: My name is [redacted] Are you aware, for the HSC, of the number of undiagnosed children and in pregnancies with this condition? I have a [redacted] that went undiagnosed for [redacted]. [redacted]until [redacted] was in advanced stages of heart failure. [redacted] couldn't be moved for two days from [redacted] to the Royal, how do you expect them to get to England? It is not realistic – you have to stop and be realistic. The HSC has to take responsibility for the lack of acknowledgement around all of the hospitals around NI, except the Royal – [redacted], all those other hospitals, there is no knowledge of paediatric cardiac procedures. They don't have clue. [redacted] had 8% of a heart function when it was diagnosed. And on the same night, the doctor in A&E guaranteed my [redacted] that there was nothing wrong with [redacted] heart, until [redacted] refused to go home. I wonder if the HSC was made responsible for every time they misdiagnosed a child, would you then realise that maybe it is not about sustainability. It is about keeping children alive.

MMcC: If Frank were here, he would say what he has previously said, there are different groups of children with congenital heart disease. There are the ones that

are diagnosed during pregnancy, so at birth we know that they may need surgery or at least will need cardiac care. Those that are diagnosed a few days after birth because their colour isn't good, or not feeding, or obviously breathless. And then those that are born, go home as healthy babies and come back in, sometimes weeks or months later, because they are developing symptoms. And that is a real issue that is important. The paediatric cardiology service is vital. I know they take referrals from all across NI. And they do clinics out in hospitals out in NI, and those are kind of things that we need to develop, because that is a key area. Lots of children who are healthy as they leave hospital and of course nowadays mothers and babies go home earlier; and then they go home and don't do very well.

P7: There is a lack of knowledge in NI. If you take away Belfast, you are taking away the hope that the people have.

MMcC: The cardiology team in Belfast is the platform on which we still need to be building our support for babies and for them as children as they grow up. That will remain and be developed to provide that service. There are areas in every service that we can do better, and we would aim to do.

WA: Is there maybe an argument about the outreach clinics – for there to be more of that? There was a piece in the paper today about how many men had turned up to Action Cancer clinics that were specially set up for them. When we hear the kind of story that [redacted] is telling there perhaps there is more of a need for that?

P7: But it takes a specialist first?

WA: But you can't have a specialist in every single hospital – or can you?

P7: But that is what I am asking HSC to make more knowledge in other hospitals. Nine times is unacceptable. If [redacted] had have come from hospital that night, we would not have had [redacted] the next day. The doctor in A&E guaranteed - put his hand on [redacted] heart; when my [redacted] refused and demanded an ECG was done, [redacted] was never seen again. From this has come about, the amount of families that I have spoken to that have been in the exact same situation has happened, the HSC is lucky that they are not dealing my [redacted] death and a lot more.

P12: On that point of maintaining the service in Belfast, and enhancing the service in Belfast, the reason behind is that my [redacted] was [redacted] old this year when [redacted] was diagnosed with a congenital heart condition that was missed twice by previous consultants. We went to Belfast, before they even did all of the tests, and scans, the consultant felt down on [redacted] chest and knew then that there was something wrong and asked us if anyone had mentioned an enlarged heart before. I will never forget that because, [redacted] had [redacted] surgery [redacted] ago today. They are fantastic. The intensive care was fantastic, the nurses in Clark Clinic; the surgeons, the consultants, I can't fault anything and I think it would be sad to see it go because once it is gone, it will never be back. I think that is the road we should be heading

down. Enhancing and maintaining the service here on an all island basis. Not only my [redacted] now, but all of the future children born and diagnosed with heart conditions, in the next months, next year, next five years and I believe that is the way we should be going with this.

P13: My name is [redacted]. On this point, Mr Poots is going to listen to you as a panel – you are going to have to reinforce what everyone in this room is saying, as strongly as you can. I know Irwyn has said that he hasn't seen any better model than Belfast and Dublin. You are going to have to reinforce that for us. Mr Poots is going to listen to you and I don't think you will want to be responsible for the service being taken away from Belfast, that's what I can gather here. It is up to you. He wouldn't have appointed you if he wasn't going to listen to you. Miriam, you did say that there wasn't a decision made, and it was going to be Mr Poots who was going to make the decision, but he is going to listen to you.

RB: And to clarify, both Sarah and Irwyn are strong voices on the working group and the opinions are being heard absolutely.

WA: Can I ask how many of you are here because you have close relatives who have needed to use the Clark Clinic? [A majority raise their hand]. So it is very important to you then. Is there anybody else who has come along for that reason who would like to say something? You can also get in touch by email, by writing to us and so on. I know you have had a real problem in your family, and are still going back and forth to [redacted]. It is the kind of information that informs the debate? Tell us about it.

P14: We stayed in Belfast for six months whilst [redacted] was still sick. Then we got told by Dr [redacted] that [redacted] needed a [redacted], and had to go to [redacted] and we were for a month or six weeks. At the minute, Belfast is sharing care with [redacted] but this last while we haven't seen our consultant. We have been told he is in meetings, or away, but if it is shared care, why are we not seeing the main man himself? Because when we go to [redacted], we always see Dr [redacted]? [redacted] is doing very well now – only for Clark Clinic, we wouldn't have had [redacted]. We were told we were looking at a fortnight if things didn't get any better. We thank the doctors and nurses up there.

P15: My name is Bert Johnson, and I am a member of Fermanagh District Council. I was elected to speak for the people. There are seven of us here tonight, and bearing in mind that we had another meeting with Roads Service tonight, that would have kept our numbers down undoubtedly. I was very interested to listen to the panel. I was very encouraged to hear from Irwyn that in 2007 that the option he was interested in then. I think his option is a good option. There are people in the Republic of Ireland who would be very happy to buy their services in Belfast and to come here. There is another thing that we want to take into account that us in County Fermanagh – we have a two hour journey to go to an airport, sit for an hour

and a half – that is a long time to be hanging about, especially for a sick child and I think that these are points that need to be taken into consideration. And I think that is very important. I am here to support the campaign to keep the service in Belfast. That is very, very important. 'Hands up for local heart surgery'. My hand is up for that in Belfast, and that is where it should be. And I think we want to fight for it. When there wasn't proper consultation for the people of NI, we want to have our consultation now and throw our weight behind it so that we ensure the service is kept here. The option that Irwyn went for in 2007, that option should still be there.

WA: There is another gentleman in front:

P16: My name is [redacted], and I am from [redacted]. I have [redacted] children and [redacted] seven. We knew when [redacted] was going to be born, a couple of months before [redacted] was going to be born, that [redacted] was going to have [redacted]. But we weren't aware at that stage that [redacted] was going to have a heart condition. Rather than [redacted] being born in [redacted], it was recommended that [redacted] would be born in the Royal, purely because the professionals would be there if there were complications. That is a concern of ours, where would we go, if the professionals are not in the Royal. Listening to everyone here talking, we are talking about saving children's lives. Of the 140 operations that are carried out in the Royal, how many of the children died? Are you saying that by all of those children going across the water, more lives would be saved? I wrote down four words when listening to Miriam, and I heard them over and over again: score; commissioned; activity; specification. If I was to go home to my children and wife, and grandparents, and aunts and uncles and read them out those four words, do you think they would know that you were talking about my child's health?

WA: Dean?

DS: The points you make are fair in terms of the language that is used within the document. We have sought to make it as straight forward as we can, but we would acknowledge that even with the input of Sarah, Irwyn and others around the table that there is still some quite technical language within the document. The challenge is for us has been – and we have spent a long time trying to make it as straight forward as possible. But to do it too much you lose something within the document. But your point is well made and it is a live issue with us at the minute, about what we might do to help make the document more accessible. If we haven't managed to do tonight, and I know Miriam sought to during her presentation, if we haven't managed in straight forward, non-clinical lay person's perspective explain what that terminology is, then we will try harder to do that at future events.

WA: Miriam, what about that concern of [redacted] about [redacted] little [redacted], what would the situation be as regards to someone like [redacted] who was advised to have the baby in Belfast, but if there is not going to be that 24/7 cover, what would happen then?

MMcC: We know that a number of children can be diagnosed antenatally. I know with your [redacted] they were obviously concerned that there might be a risk, and heart defects are not uncommon in children with [redacted]. So they obviously took very sensible precautionary approach of having [redacted] delivered in a specialist unit, so that the cardiology team would be at hand if things were needed. And neonatal intensive care and other aspects would be available. And that would be a sensible approach. As far as I am aware, there are a very small numbers of mothers who during pregnancy may travel to deliver their child elsewhere, like Birmingham, because the doctors know that the complex heart disease is going to be sufficiently complex that they know he/she is going to require surgery in a highly specialised unit. But that is a very, very small number. I hope that support around the time of birth helped and made a difference both to your [redacted] and the rest of the family.

Can I just come back – the language in this report is not easy. It is not an easy report to read. It is not a user friendly document, but we are doing what the Minister asked us to do. But beneath all of that language, and terms like specification which we can't avoid using, there is a key description of this document is trying to define: what is the best way to deliver services to children in NI so that we maximise the possibility that they do well and have healthy lives and we minimise the risk? At the end of the day that is what it is all about. We do not have a preconceived idea of what that best way is. This is an opportunity to hear what the best way is. What we do know is that we have a report from Sir Ian Kennedy that says that there are some potential risks in the way we are delivering care right now, because our numbers are so small, with the best will in the world, we can't have a surgeon available 24/7 but that in itself is a potential risk. We have to answer, what is best for our children? We recognise in all of that, and it is written large in the report, that there is a balance in everything we do…that some children will need emergency care. We have to look after that, that has to be a priority. Most, thankfully, need planned care where there is a bit more time to plan and consider where surgery can be delivered, how it can be delivered. But there is a balance in everything, and that is what we have tried to tease out in this, to make clear what the balance of risk and benefit so that people can look at it and respond. I feel like apologising as soon as I get up, because I know this is not a document that is easy to read and easy to understand in the way that normal consultation documents are, and I think if it hadn't have been for Sarah, and Irwyn and the parents around the table we would have lost the ability to actually have real issues that affect families reflected as much as we have – that has been really important.

P16: It is about saving lives. That is simple language. That's what it is about

WA: I will take a quick word from [redacted] and from you sir, and then I want to ask you a couple of questions. [redacted]:

P17: All I hear time and time again is small numbers. NI as a population is a smaller population in comparison to mainland. Congenital heart defect is the number one

birth defect. If this is taken away, what is going to be next, because all our surgeries are going to be small since we are not a large number?

P18: That is the exact point I was going to make. Will there be cancer care – small numbers – will be moved to Birmingham or Liverpool? What's next on the hit list? I am sure there are plenty of other services with 90 operations or 150 operations or treatments in the year. Are they then going to be moved on? If this one goes, what else goes?

P19: My name is [redacted]. My little [redacted] is [redacted] old has very complex cardiac issues. [redacted] had [redacted]. [redacted] had a [redacted] and ended up in hospital much longer, thankfully [redacted] was in Belfast so I was able to see my other kids. Over the summer [redacted] had [redacted]. [redacted] lost her [redacted] for a few months, genetics, trying to find a syndrome. We have an amazing team in Belfast that know her so well. To send [redacted] over to Birmingham, [redacted] would just be a statistic. We have a lot of confidence in the team here in Belfast. There has been a few cases in the media that causes me concern of children, there was a boy in Leeds who died; more recently a girl in Birmingham, they are understaffed and under pressure, over worked and underpaid and all the rest. Do we want to send our safe service over to England? They can't cope.

WA: Thank you for that. Just to address the "what's next" question.

MMcC: [redacted], your little one has obviously had a lot of complex issues and I am sure it has been really difficult. This is not an issue of what's next. We are looking at one service. But just a reminder that it is inevitable with our population of 1.8 million that we will seek some specialist care from other places; and there are a number of procedures that children from NI travel for. I sit on a panel that sits every Thursday that looks at requests for individual children to access in other parts of the UK. And of all those requests, and it is for the entire population, a very high proportion are for young people and they are for things like complex epilepsy, any epilepsy surgery, bone marrow transplants, some of the gastrointestinal because that is really complex as well, some of the genetic abnormalities, and I think it would be fair to say that as a service and as parents, nobody wants their child to travel but there are some things where it is not realistic for us to have that real expertise and we have to rely on other places for small numbers of children. I recognise that small numbers of children travelling is a lot of stress for a lot of families including those children, but I have been involved in things like paediatric epilepsy where the benefits of sending the child to Great Ormond Street and having that expertise in spades in terms of the benefits that they get of expertise, surgery, help with their medicines, help with special diets, etc. So while it is not necessarily what we would to do if we could – if we could deliver everything in NI and do it at the right standard we would do that. But inevitably sometimes it is better to travel for the expertise. But that is just a general comment about services, and we would continue to do that for some

services where it is for the benefit of the individual. The ongoing care is back here with the paediatric neurologist or cardiologist or local geneticists who are fabulous in the services they offer. Get that expertise, and then they provide that on-going care. And that is a balance that is probably struck in all parts of the UK. If you lived in Leicester, Leeds, Newcastle you access expertise from London and then go back to other centres. That is just a reality – and it is a reality partly because the specialist care is increasing all the time. There is more and more that we can do for children with complex disorders, that can really help them and therefore we need to be able to access more when it is available wherever that is.

WA: I said I was going to ask you a couple of questions. They are at the bottom of the screen. I get the feeling from the group that although when I asked you at the beginning if there were other options to be considered, the options that you want to be considered are there. For instance, primarily from providers in Belfast and Dublin or am I right in thinking Belfast, Dublin and wherever your child is going to get the best care? Is there somewhere else that should be on there?

P3: At the end of the day, my child has lots of consultants, in [redacted] here. The one person who I trust with his life completely is Dr [redacted] in Belfast. He knows my [redacted] like the back of his hand. Whenever things went wrong in Birmingham with us, dark, dark days, he rang me to see if I was ok. The level of care is more personable. He knows [redacted] very, very well. And he was as gutted as we were when things went bad. You just don't get that over in England. Yes, the surgical team are amazing. The intensive care is amazing; the ward is like a cattle mart. It is just extremely busy, no harm to the nurses because they are understaffed, they haven't got the time to help you. You are on your own, and to send more people over there is insane.

WA: It has been really useful for everybody to hear all of your views and I hope that all of you who have wanted to say something about this have done so. If you haven't, and you want to say something before the end, please do. Given the time, and we have talked for longer about the options, as far as the criteria are concerned. You have to have some way that you have a measure of what's important. Has anyone got anything in particular that they want to bring up about this? About the weightings… safety and sustainability is the most important in the weightings and so on. In time… volume… accessible… services in Belfast… resources. Yes – [redacted].

P5: I want to give the floor to the parents tonight as I think it is important that their voices are heard, but sometimes I get more disillusioned with consultations as time goes on. A few years ago, and it is not dissimilar, we were told that to close the A&E in Belfast City Hospital was the way forward, and let's move everything where we can get a better service in the Royal Victoria Hospital, where more patients can be treated immediately. That happened, but tonight I hear on the news that we have a [redacted]. My

fear is, are we going to go down these roads where people are going to be, as [redacted] has already said – she has seen what it is like in Birmingham. We need to get a real degree of rationale into this here, and be very careful what we wish for.

P21: I am surprised that point one Safety and Sustainability is going to be weighted together, when safety and sustainability has been made such a difference in Sir Ian Kennedy's report. I think that safety should be a point on its own. Sustainability should be a point on its own, and at the very bottom of the list. Safety at the top, sustainability at the bottom. Everybody would want the procedures to be carried out safely, but I don't think sustainability is relevant. More and more cases, doctors become tired, more mistakes are made.

DS: It is worth coming back on that, and what is meant by sustainability. It is the consistency with which the model is put in place can be delivered and is able to be resilient, which is what I was getting at as opposed to keeping provided into the night etc. The difficulty is that if the model that is put in place is not resilient and able to deal with lumps and bumps and not able to deal with a doctor being poorly and unable to come in, it then becomes intrinsically unsafe so the two things are two sides of the same coin. That is why the working group took the view that safety and sustainability should be the one criteria.

P7: I have mentioned this a few times but nobody has given me a response back. The safe and sustainability believe you need to be in high figures. But Sir Ian Kennedy's review found Bristol to be safe - because of their high figures that they were carrying out it has now been found unsafe. Can you please bear this in mind? When you are talking about safe and sustainability – remember that Sir Ian Kennedy's safe and sustainability's figures that he is using are now found to be unsafe. Please answer that.

MMcC: Just to reiterate by safety and sustainability we tend to think it is the ability to provide something 24/7 365 days a year. In order to do that the safe and sustainable standards would say that you need to have at least four surgeons on the rota – and maybe more because that is still pretty busy. In order to have four surgeons on a rota, each surgeon needs to do at least 100 procedures on the basis that the more procedures you do, the better you do them. Actually they would stretch that with the goal of doing up to 150, but a minimum of 100. You have four surgeons working together as a team on a single site; they are each doing 100 procedures which means they have lots of experience, and a breadth of experience. The cumulative effect of that is four surgeons and 400 procedures. That is what sustainability is. That ensures whether you turn up on Christmas Eve or Monday morning for a regular list you have the same kind of quality care. In terms of the comments on Bristol, I don't know the details. I am not aware if it was said to be an unsafe service.

[You should be aware, this is the future of our children in NI.]

At this point, our consultation asked for options about whether it is an option to have some services provided in GB. We have not gone down to the detail of which units in GB. That is a separate thing which needs to await the outcome of the consultation. But we are conscious of the warnings around Bristol and the actions they have taken to remedy shortcomings.

P7: This was due to staff under stress. Is that not worrying for everybody? Maybe our smaller numbers are safer in NI?

P22: A [redacted] back here asked a question that wasn't answered. There was between 90 and 140 operations a year, and unfortunately a number of them operations didn't succeed and a number of children died. Is anyone saying that if a number of those operations had of been in Birmingham that we would have had a more successful outcome? Or not?

MMcC: The evidence is that surgeons who do more procedures tend to have better outcomes. Across the UK there is a database that every cardiac unit contributes to. It is called the CCAD. That might have been set up after the Bristol problems in the late nineties. CCAD database is a mechanism where the details on every single child who has surgery and very significant details are put into the database, so that across the UK monitoring can take place to identify if there are any early indications of problems in a particular unit, with a particular surgeon or with a particular procedure or with particular groups of children. So that is a really important tool. That has probably pushed up the quality of care across the UK but it provides a monitoring system for the data in terms of the deaths. There are for all units across the UK, in terms of statistics, they all fall within the limits so there is no unit within the UK that is seen to be what is an outlier or with poor performance, as unfortunately this is not the easiest thing to measure – it only looks at death amongst children having surgery. It doesn't look at other complications. But that doesn't mean units aren't vulnerable, even with reasonably good outcomes. Oxford had reasonably good outcomes, there were issues about whether it was a big enough unit to be able to sustain a service, and ultimately they closed because it was considered that it was too small or too vulnerable – they were doing perhaps 120 from memory. But the statistics would indicate that across the UK for all procedures, there is no particular outliner. This is no unit that is doing particularly better or worse than others. The difficulty is that even across the UK, the numbers are relatively small and it takes a couple of years to see a trend, and this database looks at it on a three year basis because the number of procedures even for the UK in a year may not be enough to show the patterns.

WA: Sarah

P5: Can I just clarify on the Oxford situation – it closed down because it was found to be unsafe not because of the low number of surgeries that it was doing? It wasn't

due to their surgical numbers, it was found to be unsafe and that it the point that Dr Casey has brought up a few times within the working group.

WA: Dublin's contributing to that list as well now, isn't it?

MMcC: Yes it is, yes.

WA: I would like to move towards a close if that is ok, if you have anything more that you would like to bring up – Sarah:

P5: I just wanted to add more context to this evening. Since the start of this process, Children's Heartbeat Trust which began with Kennedy's review and its visit and recommendations, as a parents' support organisation we have expressed concern about this from the very beginning, about the timescales and the recommendations; and just to let you know that these concerns were echoed last week by our health committee up in Stormont, which is a cross party political committee, whenever last week they called on the Minister to halt the review into children's heart surgery and fundamentally review the terms of reference for considering the future of children's heart surgery. All political parties represented on this health committee have come out to say that they would like to see a halt to this review and reconsideration of the terms of reference. It is important to highlight as well as a parent support organisation, our priority is safety. That is the most important thing. We asked parents and families to come to attend public meetings across NI, and we had over 1,000 people attending that. Overwhelmingly, the people whose care for their children is priority of anybody in NI they would like to retain surgical services in Belfast as part of an all island service.

WA: Thank you.