Northern Ireland
Assembly

Committee for Health, Social Services and Public Safety

OFFICIAL REPORT
(Hansard)

Paediatric Congenital Cardiac Services: DHSSPS/HSCB/PHA Briefing

1 May 2013

NORTHERN IRELAND ASSEMBLY

Committee for Health, Social Services and Public Safety

Paediatric Congenital Cardiac Services: DHSSPS/HSCB/PHA Briefing

1 May 2013

Members present for all or part of the proceedings:
Ms Sue Ramsey (Chairperson)
Mr Jim Wells (Deputy Chairperson)
Mr Roy Beggs
Ms Paula Bradley
Mr Mickey Brady
Ms Pam Brown
Mr Gordon Dunne
Mr Samuel Gardiner
Mr Kieran McCarthy
Ms Maeve McLaughlin

Witnesses:

Mr Jackie Johnston	Department of Health, Social Services and Public Safety
Dr Heather Livingston	Department of Health, Social Services and Public Safety
Mr John Compton	Health and Social Care Board
Mr Dean Sullivan	Health and Social Care Board
Dr Miriam McCarthy	Public Health Agency

The Chairperson: I welcome Dr Heather Livingston, Mr Jackie Johnston, Mr John Compton, Mr Dean Sullivan and Dr Miriam McCarthy. Members have a lot of questions, so I ask that we stick to a 10-minute presentation, after which we will open it up for questions from members. You will know that, at times, I allow others to respond, but we should, as much as possible, stick to one person in the delegation answering questions. You are more than welcome.

Mr Jackie Johnston (Department of Health, Social Services and Public Safety): I will make a few opening comments. My colleagues and I are very grateful for the opportunity to speak to the Committee about the review of paediatric cardiac services in Northern Ireland. I am accompanied by John Compton and Dean Sullivan from the Health and Social Care Board, Miriam McCarthy from the Public Health Agency (PHA) and Heather Livingston from the Department. If members are content, I will recap on the background to the review, the consultation process and outline the stage that we have now reached and the next steps in moving forward.

Members may recall that the Minister made a written statement to the Assembly on 29 March last year advising of the Health and Social Care Board's intention to undertake an external review of paediatric congenital cardiac services (PCCS). In a further written statement to the Assembly on 1 August last year, the Minister announced the publication of the expert panel's review of PCCS in Northern Ireland. Although the report did not find any immediate safety concerns presented by current arrangements, it concluded that the surgical element of the service is not sustainable and that the potential safety risks should be addressed within six months. In light of that, the Minister asked the board, working with the PHA, to draw up a document to include the following areas for formal public consultation: a commissioning specification for the future delivery of PCCS and clear criteria to provide an objective basis for future decisions on that and related services in Northern Ireland. In addition, the Minister charged the board with ensuring that there should be the most robust retrieval and transport services available to ensure that patients could be moved quickly and safely, particularly in emergencies.

The consultation document was approved by the Minister, and a 12-week consultation was launched on 25 September, running to 21 December last year. The focus of the consultation was on a framework for the assessment of a preferred way forward for the commissioning of PCCS services rather than an option itself. In February of this year, the Minister approved a post-consultation framework document, which included a final service specification, eight options for future commissioning and a scoring matrix agreed by the PCCS working group that had also been set up. He then asked the working group to take forward the scoring of the eight options in order to identify a recommended preferred way forward or preferred option for the future commissioning of that service. The working group has now completed that stage of the process and recommended the preferred way forward. That recommendation was approved by the board at its meeting on 25 April, and has now been submitted to the Department for the Minister's consideration.

The recommended option involves building on the existing service provided by the Dublin paediatric cardiac surgery centre for the Belfast Trust. The Minister has repeatedly stated that his key priority is to ensure the delivery of a safe and sustainable service for those vulnerable children and, in so doing, he wants to ensure that we have fully explored every possibility for addressing the concerns of parents and consultants on that important matter. Therefore, before he makes his decision, the Minister wants to hold further discussions with our counterparts in the Republic of Ireland and explore the scope for flexibility in the location for the future delivery of the service without compromising any aspect of patient safety. He will then make his decision shortly afterwards.

I hope that the Committee finds that helpful. My colleagues may wish to add to it; otherwise, we are happy to take questions.

The Chairperson: OK, Jackie, thank you. We got the paper, which outlined the issues. Thank you very much for it. You talk about the service being safe and sustainable. Explain that to me. What does that mean?

Mr Dean Sullivan (Health and Social Care Board): Ultimately, it means two things. It means that any child going in to receive care at any time of the day, on any day of the week and in any week of the year receives a standard of care that is safe. It does not mean that it is safe sometimes but not at others; it does not mean that there is emergency cover sometimes and not at other times; it does not mean that, with a bit of sickness, the service falls over. It means that you have a safe, robust service, consistent with prevailing standards, that is sustainable 365 days a year, 24 hours a day, seven days a week.

The Chairperson: That it is sustainable?

Mr Sullivan: You asked what a safe and sustainable service is; that is what a safe and sustainable service is to me.

The Chairperson: We have been told that the service is safe but not sustainable. What does that mean?

Mr Sullivan: Although last year's review did not identify any immediate safety risks with the Belfast service, it did identify material difficulties with its sustainability, which would present risks over time in the continuation of care. In light of those risks, the recommendation was that appropriate action be taken within six months to make a change to those arrangements.

The Chairperson: What is the main reason for it not being sustainable?

Mr Sullivan: Miriam may wish to amplify parts of this. One of the things that the working group sought to do — and did do — at the Department's request was to identify appropriate standards for a service for Northern Ireland children against which we would judge and seek to commission paediatric cardiac services for children in Northern Ireland. Those standards included 24/7 surgical cover and that the unit providing the surgery would already be delivering at least 400 procedures a year, or, at the very least, working towards that.

Against both those standards, the service in Belfast falls well short, as set out in the papers that I believe you have seen.

The Chairperson: Therefore, at present, the service is safe, but its sustainability is down to the fact there are not in and around 400 procedures a year?

Mr Sullivan: That is one of the fundamental challenges associated with the maintenance of surgery in Belfast.

The Chairperson: I get that. Was there an option for clinicians to go anywhere else to get the additional procedures?

Mr Sullivan: A range of options was considered. In the initial consultation document that was issued in September, six different options were highlighted, and two further options were identified and informed by the outcome of that consultation process. I believe that all possible options were considered through the work of the working group, including clinicians who perhaps work elsewhere coming to work in Northern Ireland, and also the idea of establishing Belfast as a centre of excellence, with kids coming here for treatment. There was any number of combinations of doctors and children moving to identify an appropriate way forward, but many of those options presented significant difficulties because of their practical deliverability.

The Chairperson: OK. Why did the board come down on the side of this option?

Mr Sullivan: It is important to focus on the process. The board did recommend that option, but there was a significant process leading up to its recommendation, and it might be useful for members if I rehearsed it. At the Minister's request, the board established a working group that included a cross-section of representatives from the two main parent organisations in Northern Ireland; clinicians' representatives; representatives from the trusts, including the Northern Ireland Ambulance Service Health and Social Care Trust and others; commissioner representatives; and the chief executive of the Patient and Client Council. A wide cross-section of members, as well as board and agency staff, was around the table.

The working group worked up the consultation paper, in which there was a draft service specification, a list of options and the criteria for assessing those options, as requested by the Minister. That was agreed in full by all working group members. Following the completion of the consultation process, the working group unanimously agreed to a revised version of the service specification, informed by the outcome of the consultation process and, as I said, agreed to a slight broadening of the number of options from six to eight. All of us agreed to the final criteria and the associated weightings. All that was agreed. All but two members of the working group agreed on the application of the criteria to those options. Taking account of all the pros and cons of the eight options, the working group agreed, with two exceptions, that the best way forward for children in Northern Ireland was to deliver the surgical part of the service in Dublin and to continue to undertake the vast majority of interactions with services — the in-patient cardiology service, outpatients, and so on — in Belfast. That was not part of the review.

The Chairperson: John, initially, there was the possibility that the service would move to England?

Mr John Compton (Health and Social Care Board): Yes.

The Chairperson: At that time, was the board doing any work on the possibility of the service moving to England?

Mr Compton: It is important to be clear that there was and has been a long history of small numbers of children moving to England for particular surgical interventions. Therefore, we certainly considered that; it became part of one of the options. However, in listening and paying attention to parents' requests in particular, we were very keen to see whether we could construct an all-Ireland-based solution, and that is the solution there. We did not approach it with a predetermined view that the solution should be in England, Dublin or Belfast; we wanted a decision that would work.

The Chairperson: The reason I ask is to find out whether there would be provision if kids here needed emergency treatment.

Mr Sullivan: No one option was explored above any other. As I said, there were eight options. When we consulted previously, there were six, one of which was that all surgery would be undertaken in GB. That is known, and we have not sought to move away from that. Some working group members visited units in England. Equally, we visited the unit in Dublin and the unit in Belfast because, as chair of the working group, I would not have wanted, through John and board colleagues, to make a recommendation to the Minister without having seen the units. As I said at the public board meeting last week, a crucial decision was made by working group members. In the context of the service specification that was agreed, because of the need for timely access to emergency treatment, which is set out very specifically in the service specification, the time it would take to fly to England, and the potential risks associated with the journey — even when it works quickly despite a slow start — we could not reliably and consistently assume that that was an appropriate way forward. That meant that we had to find a solution on the island of Ireland for the relatively small, but still significant, number of emergency procedures that are required each year. That took away the idea of a GB-only option.

The Chairperson: What part of the evidence that you had before you or that you collected on visits made you come down on the side of the option that you have suggested?

Mr Sullivan: Do you mean the Dublin option?

The Chairperson: Yes.

Dr Miriam McCarthy (Public Health Agency): We carried out a robust process. At the outset, we identified a service specification and tried to establish the kind of services that we wanted for children in Northern Ireland. On the basis of that, we developed clear criteria against which we could consider any option.

In the working group, we spent a great deal of time thinking about the criteria and what the key issues were. Those issues included: whether the service was safe and able to deliver against standards; whether it could meet the needs of children in emergencies; whether it was accessible — no one wants to be away from their wider family for longer than necessary — whether it could accommodate the activity of children from Northern Ireland; and whether it could establish clinical linkages. We also looked at cost-effectiveness, but we did not give it the same priority. Having established the criteria, we spent further time looking at the weighting of those criteria and deciding which were most important and should have the greatest emphasis.

Over many meetings, we went through a robust process of looking at each of the options — GB only, GB/Dublin, Dublin only — and thinking about how a particular option met each criterion. It was done systematically and rigorously. On the basis of that, two options scored most highly. On those — Dublin and Dublin/GB — we recognised that scoring is not everything; that there is a qualitative aspect and that sometimes issues are not fully captured in scores. Therefore, we looked at particular aspects that would have a qualitative bearing on one or other of the options and explored them in detail.

That was the process that we developed over quite a number of weeks. It was not just a gut feeling; it was based primarily on the ability of any option to meet each of the criteria. The criteria were based on our service specification, which was the very first thing that we did when we got together last August or September.

Mr Sullivan: Miriam makes a significant point: this was not done quickly or straightforwardly; it was approached methodically over a prolonged period and ensured the full involvement of all relevant stakeholders. The working group was first established in August last year and met every week but two weeks — one week at Christmas and one at Easter — from August until the middle of April.

The Chairperson: Nobody is questioning the work, Dean. You have a job to do and we have a job to do. I am not for one minute —

Mr Sullivan: I was not making a point about the work involved; I was making one about the involvement of all the stakeholders.

The Chairperson: I, for one, would not think that individuals came at this willy-nilly; no one is suggesting that.

In the Assembly last week, the Minister said that he wants to look at all the options and other issues. This is a hypothetical question. John, suppose the Minister says that he has had discussions with James Reilly and they have agreed a ministerial decision to have one service on two sites. Can that be done?

Mr Compton: Politics get involved, so Ministers will have their views. I can only relate that when we directly asked the Health Service Executive (HSE) in the Southern jurisdiction how practical it would be, whether they would be prepared to see a twin-centre site, and, therefore, whether they would be prepared to refer several hundred children to North of the border so that we could work in that way, the answer was no, they would not.

The Chairperson: The HSE said that?

Mr Compton: Yes.

The Chairperson: It was not a ministerial decision.

Mr Compton: No, it was not a ministerial decision; it was a service decision. The HSE said no for exactly the same reasons. The criteria have a numeric denominator. Although the Dublin service is one of the largest paediatric cardiological centres on the two islands, I assume that they believed that the removal of 250 to 300 children would destabilise the service that they have and they are, therefore, reluctant to consider that option. However, politics is politics, and Ministers are Ministers. If the Minister can secure agreements that we cannot, we will have to take account of that in due course.

Mr Wells: You said quite clearly that, as a result of your weightings, this is the best option. However, it may not be the right one, in the sense that it may still be below what our community and our children need. Are you rigorously testing the option to see whether it will deliver? For instance, there is doubt about our capacity to get children in time from, say, Coleraine, Ballycastle or Larne, which are an extremely long way from Dublin. There may not be capacity to get children to Dublin — to Crumlin — in time. Has that been looked at?

Mr Compton: There are a couple of things that I would say in response to that. We have had a recommendation, and that will be followed by an implementation process that we would not rush. Transport, as we said at our board meeting last week, will be central. However, we reminded board members about the changes in the transportation system that we have recently approved. We have substantially enhanced the transportation system for paediatrics in general in Northern Ireland, and that would be helpful as far as this is concerned.

Moreover, there are substantial travel distances involved in the Southern jurisdiction, and they happen successfully. It is entirely possible to organise successful travel. Children come from Cork and Kerry, and from the west of Ireland and Galway, to Dublin for procedures, so it is entirely possible to organise transport arrangements. If the Minister endorsed the decision that we, as a board, recommended to him, there would be an implementation process. The timetable would be key in that implementation process, and in it would be transport arrangements.

It is also worth pointing out that, today, most emergency surgery that happens to youngsters in Northern Ireland takes place in Dublin. Today, as we sit, that is the current interim arrangement.

Mr Wells: However, you will add considerably to the demand on the hospital, which I think is called Our Lady's Children's Hospital, Crumlin. On foot of your decision, the BBC went down and filmed that ward. It looked very busy; it looked to be at full capacity. What guarantee is there that a child will not arrive from Coleraine or Ballycastle in that hospital and there will not be the capacity to treat them in an emergency?

Mr Compton: If you watched the programme, you will also have seen a consultant surgeon who described very clearly an emergency involving a very small child who had a particular problem in Belfast that emerged very late in the evening. The youngster had been transferred appropriately and quickly, and was in theatre in the early hours of the morning and was successfully treated. So, although it is a busy unit, it is used to dealing with emergencies 24/7 and with those that come in at all times of the day and night. When we were looking at the options, we asked those involved whether they were entirely confident that they could handle the volume of activity. We need to think about the activity in two groups. One is emergency activity, and those involved are of the view that they can deal with the emergency activity immediately. Elective activity — in other words, the planned activity — is the second group, and those involved said that they would need some planning to sort that out. We would be very happy to work with them on the planning of that once a decision is taken. We believe that, if that were the case, it would practical and possible to make the transition in 2014.

Mr Wells: Are you basing that simply on the fact that Mr Reilly, or your equivalent, in Dublin has said, "No problem, Mr Compton", or are you looking at cold, hard stats to test that that is correct?

Mr Compton: We are very much looking at the cold, hard statistics to test that out. To be fair to our colleagues in the Southern jurisdiction, I do not think for one minute that they would say to us that they could do something in the knowledge that they could not. That is not the issue. They are very keen to assist in supporting us on this difficult issue. So, I do not believe for one second that they would say to us that they could do something when, in fact, it was impossible or unlikely to happen.

Mr Wells: Finally, I think that this issue also needs testing. There is a view that, if you remove a large amount of the surgery from Belfast, other ancillary services will also wither on the vine because the complex cases will simply not be dealt with. Those services will die a death, and there will, literally, be no provision at all.

Mr Compton: I understand that. Where the recommendation is concerned, it was quite clear at our board meeting that we planned to invest very substantially in the cardiology service, which I think is the principal service that you are talking about. If the solution came to pass, we would have networked arrangements where the clinical staff in Belfast would work in Dublin on certain days of the week to maintain their skills and expertise. We are very keen to have a very successful cardiological service for Northern Ireland. That will mean investment in Belfast and in some of our principal sites, because, to be honest, one of the things that we have not quite got right is the networked arrangement for cardiology services in, for example, the Craigavon and Altnagelvin hospitals of this world. So, we want to make that network much more robust and much stronger. That is part of the total solution.

The Chairperson: Jackie, how will the Department assess the robustness of the board's recommendations?

Mr Johnston: The Department will take advice from its clinicians. Heather, do you want to say a word about that issue from the clinician's side?

Dr Heather Livingston (Department of Health, Social Services and Public Safety): As the Minister said, safety is the priority for the children, and we want to look at the very detailed recommendations from the group, have discussions with the clinicians here and get assurances from our counterparts in the Republic of Ireland that robust and sustainable systems will be in place.

The Chairperson: Jim made a point about a child in Ballycastle. If a child in Ballycastle needs a service, do they go to Belfast and then get referred to Dublin?

Dr M McCarthy: It is hard to say what will happen to every child, because each situation is different. Typically, emergencies arise soon after birth: a baby is born and does not look great, so medical and nursing staff need to investigate. Typically, in those situations, at the moment, the child comes to Belfast first, because that is where the paediatric cardiology service resides and where a more detailed diagnosis can be made. Then, depending on their condition and on the degree of urgency, the child may or may not be referred onwards. The reality is that, over the past number of months, all the emergency cases have gone to Dublin, other than the few that would have gone to Birmingham and that have been going there for years. The vast majority of the urgent cases, which are those that need dealt with within a number of days, are stabilised and go to Dublin.

If the option for Dublin to be the surgical provider were pursued, the pathway that would be in place would need to be worked out for particular conditions, and there would obviously be a degree of clinical discretion in whether a child may go directly from an acute hospital to Dublin or still go through Belfast. So, it is hard to be prescriptive about that. We anticipate that the paediatric cardiologists will still be centrally involved in making the diagnosis, because that is a key element. We also anticipate that they will continue to be centrally involved in the children's ongoing care. It is worth remembering that we have around 100 children who need ongoing care for cardiac conditions. Of those who need surgery, thankfully, the vast majority will need surgery only once in their life, but they need ongoing care from the cardiology team, sometimes for the rest of their lives and sometimes for most of their childhood.

The Chairperson: I appreciate all that, but I am conscious that we want to try to get in to where we are now. I am sorry for cutting across you. We have the recommendation in front of us. Jackie and Heather, there is a possibility that a child in Enniskillen or Ballycastle will need to go to Belfast and then on to Dublin. If that happens, who in the Department is responsible? The boards made their recommendation, but who in the Department is responsible for advising the Minister on whether to accept the board's recommendation?

Mr Johnston: The ultimate advice will come from the permanent secretary to the Minister, based on the board's recommendation and whatever other considerations are taken into account. As you know, the permanent secretary takes advice from the Chief Medical Officer and colleagues about the clinical issues on the future of the service.

The Chairperson: Now that the recommendation has been handed over formally to the Department, how many people in the Department are working on this?

Mr Johnston: I am working on it, as are Heather and Catherine Daly.

The Chairperson: Will you then feed in to the permanent secretary, who will advise the Minister?

Mr Johnston: Yes.

The Chairperson: Do you have an idea of a time frame for that?

Mr Johnston: We are hoping to do it as soon as possible. I do not want to speculate.

The Chairperson: I hear you say "as soon as possible", but I also hear that 100 new houses are being built as soon as possible. Give us an idea.

Mr Johnston: I would say that it is a matter of weeks.

Ms Maeve McLaughlin: My question is in a similar vein to the Chair's. Given that the Minister has talked about the need for additional conversations with the Twenty-six Counties, for the record at this stage, who makes the final decision? There has been a lack of clarity about that process.

Mr Johnston: The Minister has repeatedly stated that it is his decision, so he will take the final decision.

Ms Maeve McLaughlin: So, it will ultimately be the Minister's decision?

Mr Johnston: Yes.

Ms Maeve McLaughlin: How will that be communicated? There is an issue about parents' involvement and about Assembly involvement. Will it go to the Floor of the House, or will it go to the parents?

Mr Johnston: I imagine that the Minister will want to communicate to the Assembly and use it as the medium for making his announcement, so it will go to the Floor of the House, yes.

Ms Maeve McLaughlin: Is that guaranteed to be the process?

Mr Johnston: That is the working assumption at the moment.

The Chairperson: Jackie, let me remind you that, a few weeks ago, the Minister had to apologise to us because that did not happen. I am saying that in case you were not aware of it.

Mr Johnston: It is the working assumption at the moment, but I will be happy to clarify that for you afterwards.

Ms Maeve McLaughlin: Ultimately, you are saying that this is the Minister's decision and that you cannot guarantee but will come back with assurances that it will go the Floor of the Assembly. That would be the protocol.

Mr Johnston: Yes, I cannot see a reason why it would not go to the Floor of the Assembly.

Ms Maeve McLaughlin: I have one further point about a shared site, if you like — an all-Ireland solution. Is the recruitment of consultants an obstacle to that?

Mr Compton: Our understanding from colleagues in the Southern jurisdiction is that they do not anticipate that there would be any difficulty recruiting staff once a decision were taken to say that this is the way forward. They are confident that, given the scale and size of their unit, they will be able to recruit the necessary staff, who would be based there.

It is also fair to work out that, however the situation turns out, there are ministerial differences. Speaking honestly — you have to speak as you see it— I think that that will be difficult, given the numbers that we are talking about. However, we are happy to be directed by the Minister on that. We will be working in a network way, which we already do, with colleagues in the South. This is about enhancing that network, because, in the end and as my colleagues pointed out, the overwhelming majority of children who need cardiological services will be supported, treated, looked after and cared for in Belfast. We are dealing with the small, very significant and very difficult situations that families with youngsters who need the actual surgery have to contend with. We are endeavouring to find the most coherent solution to that.

Ms Maeve McLaughlin: That is contrary to what the Minister said here a number of weeks ago. He indicated that recruitment on an all-island basis was an issue, because the qualifications and employment criteria for cardiac consultants North and South differ.

Mr Compton: I am sorry; I thought that you were asking whether the Southern jurisdiction would have difficulty if it had to recruit additional staff to take on the work in Belfast. I have given the answer to that question, which is that I do not believe that there is an issue there. I am not quite sure what the context is, but I think that it may be —

Ms Maeve McLaughlin: Sorry; let me be clear. I am asking whether recruitment on an all-Ireland basis to provide an all-Ireland solution on a shared site in both Belfast and Dublin is an issue. Is that recruitment an obstacle?

Mr Compton: I do not believe so. I am struggling to understand the difficulty. The issue is who the employer would be. Under our recommendation, additional staff would be employed in Dublin and they would network with Belfast in the way that existing staff who work in Dublin network in Belfast. That happens successfully. The issue has always been about whether, if we were trying to have it as a stand-alone service in Belfast, we could recruit and whether there would be recruitment issues. There would be recruitment issues in Belfast because of the scale and size of the facility. Given the volumes of activity that go through the service today, we believe that there would definitely be recruitment issues if we were trying to recruit individuals in Belfast to work in a stand-alone set-up.

The Chairperson: At the moment I have Kieran, Gordon and Roy wanting to ask questions. Any other members who want to come in should indicate that.

Mr K McCarthy: Thanks very much for your presentation. I am glad to hear that the Minister will make the final decision on this. He has said many times that he wants to see the service preserved in the Royal Victoria Hospital in Belfast. Given that, and given the continued pressure from a very concerned parents' organisation, which has mounted a really constructive campaign over the past number of months — I think that Dr Miriam mentioned the key issues and the working group — how vital were their considerations considered to be when you were coming up with the option? Although I agree and really want to see an all-island service, I want to see a Belfast and Dublin service. I am just worried that, at the moment, there is too much emphasis on Dublin and not so much on Belfast, which is against the ongoing campaign. We fully support that campaign to get the cardiac unit—

The Chairperson: Kieran, can I push you for a question?

Mr K McCarthy: — to remain in Belfast. Would you be prepared to listen to more evidence if the group came forward with tangible —

Mr Sullivan: I will kick off, and Miriam may wish to add supplementary material. I made the point not because of the workload from board and agency staff, which, as you say, is a given, but to emphasise the amount of involvement that there has been from parent groups. Both the key parent groups — Heartbeat Trust and Heartbeat NI — have been involved in all the meetings, so there has been considerable opportunity for them to have input. I think that it is fair to say that the individuals from the two organisations have made very meaningful and significant contributions to the working group's thinking. That has been reflected both in the initial consultation document that went out, which everybody agreed, and in the consideration of the consultation process, the outcome of which was to produce a post-consultation document. Again, that was agreed by everybody, including the two organisations that I mentioned. The only point of disagreement has been in the application of the criteria to the options and the concerns of one organisation about any option that would not result in surgery remaining in Belfast.

The only other point that I wish to highlight is that all the working group members also allowed other parents to be present in an observation capacity. I cannot think of a single meeting that we had that did not have at least three or four, and sometimes more, parents. So, we have certainly sought to make the process as transparent as possible.

The Chairperson: Dean, let the Department answer that question. You made your recommendation, and Kieran said that there is further evidence. You have done what you needed to, and the recommendation is now with the Department, so let us try to get the Department to tell us —

Mr Johnston: I would just like to add that the Minister's overriding concern is to ensure the safety of this very group of vulnerable children. Over past months, he has had a wide range of correspondence from interested parties — that is all available in the Department — expressing various views on the key or core issues on this particular service. He has also had a range of meetings with parents' groups and consultants, so we are fully apprised of the very wide range of views and opinions that exist on this issue.

Mr K McCarthy: If further evidence came forward to suggest that Belfast should be retained for surgery, would it be listened or adhered to?

Mr Johnston: If you send it in to the Department, we will certainly look at it.

Mr K McCarthy: OK. Finally, the press release states that there is to be new, further investment in cardiology facilities in Belfast. What exactly does that mean?

Dr M McCarthy: We picked up a number of issues in our report that the board approved that indicate that we can improve cardiology services in Northern Ireland. That is not to say that children's cardiology services are not really good — any parent will tell you about the high-quality care that is provided — but some things could be further developed.

One issue concerns having a stronger network with our acute hospitals and specifically trying to develop paediatricians in those acute hospitals so that they can have more of a particular skill in cardiology. That is in keeping with what is happening across the UK. Another example is to improve and enhance the diagnostic facilities so that children can be diagnosed with the best technology using the most modern approach. That is likely to include an MR scanner. Those are just two examples of areas where real developments are possible. They would enhance the experience for children and for parents and should be done, whatever option is pursued.

Mr Dunne: Thank you very much for coming along to deal with this issue. I think that we all appreciate how sensitive it is. Those of us who attended public meetings were struck by that. Another important factor is that the public fully recognise the skills and the service that they got at the Royal Belfast Hospital for Sick Children. Local people fully appreciated it and saw the skills at first hand. We got clear evidence at the public meetings of the good work that is carried out, and I think that it is important that we put that on the record.

Is it, as the public would think, all about making savings? At the end of the day, does it boil down to putting existing costs against proposed costs? Is it about making savings on what, as far as the public is concerned, was an excellent service at the risk of perhaps losing it?

Will the accommodation for parents and families at the Crumlin hospital be included, or will that be left to the families to deal with?

Transfer times, which are vital, have been mentioned.

The Chairperson: Gordon, is that a question for the board or the Department?

Mr Dunne: It is for the board. Where transfer times are concerned, there has been talk about air ambulances. I do not think that we are clear whether air ambulances would be available, if they are available, to deal with a high-risk patient in Northern Ireland. Depending on the risk, would they be considered for transferring people from the north coast, for example, to Dublin?

Mr Compton: I will commence with that, and my colleague can maybe follow on. First, I take the opportunity here in this public environment to support your comments about the staff in the Royal Belfast Hospital for Sick Children. I have met them, and they are fantastic. Part of what we are trying to do is enable them to continue to do the fantastic work that they have done and to not in any way disable them from doing that. So, I think that it is really important to make that statement up front.

Secondly, this is absolutely and completely not about money. What we are proposing will cost considerably more than the money that we currently invest.

Mr Dunne: Will it cost more?

Mr Compton: Yes. This is not about money. This is about the right service, safety, sustainability and quality. The money will come after, and we will invest it. For example, we are planning to spend £1 million on enhancing the cardiology services this year, and we have committed some £2·5 million to improving paediatric transfers across Northern Ireland. Should it come to pass that we will pay Crumlin hospital for the surgery that it is currently doing, we will, of course, enter what is called a service level agreement with it. So, this is not about the money; there is no issue about money's being in the background.

Mr Dunne: So, we will effectively be paying more for this service.

Mr Compton: It will cost more, and so it should. We are addressing issues of safety and sustainability, and you cannot do that if you are not prepared to invest in the service. So, we will invest in the service to deliver that.

My colleagues might want to talk in a little more detail about the three-hour standard that was agreed for access and reflect on the air transport issue. It is my understanding that air transport is not always appropriate for small children who need to be transported. There are some clinical issues that make air transport unsuitable or not proper in some situations. The real issue is making sure that we have land-based transport that works effectively and efficiently.

Mr Sullivan: John is right about the air transport. He referred to the recent case of a child who was transferred to Dublin. My understanding is that it took an hour and half between that patient's leaving Belfast and their being operated on in Dublin. The standard that all members of the working group agreed for emergency cases is that the total journey time, from a decision being made that a child needs surgery to when they are in place to receive that surgery, should ideally happen within three hours and not longer than four hours. That was the issue that made GB not a deliverable option for the emergency patients. The view —

Mr Dunne: Will you be able to achieve that?

Mr Sullivan: That was certainly the view of the majority of the working group members. As I said, two of the working group members were of the view that that would be challenging in a number of circumstances.

On air transport more generally, the view is that Dublin to Belfast is not far. By the time that air transport were made available— even if it could be made appropriate, given the various bits and bobs of kit and mobilisation time that are required — you would struggle to make the journey as quickly as you would in an ambulance. That is why is it so important that we have made the investment that we have, with £2·5 million going into the paediatric intensive care service to underpin the development of a 24/7 paediatric transport service. Indeed, John highlighted that point.

Mr Dunne: What about accommodation for parents and support?

Mr Sullivan: Key issues that came through in the consultation process were the importance of the accommodation issue and the general hygiene factors that are associated with making the whole process as straightforward for parents in what is a very stressful situation for them and their families. We have explored that with Dublin, as we did in the other visits that I referred to. If the Minister decides that Dublin is the way forward, we will seek to work with parents to ensure that not only is the accommodation fit for purpose to meet their needs but that all the other aspects of the journey are made as straightforward as possible.

Mr Dunne: OK. Thank you. Going back to the cost, we are going to pay more, but for what? Is it for an enhanced service, standard of care and quality of provision? Is it all about that rather than about the local facility that the public told us is fit for purpose?

Mr Compton: I think that it goes back to the standards that we agreed that we should work towards. Those standards were agreed by everyone, and they are about the 24/7 cover and working towards 400 interventions a year. That guarantees regularity, familiarly and sustainability. That is what we are investing in. We are investing to make sure that the children in Northern Ireland receive, and are able to receive, that service. Although the current service works extremely well for the individuals who are involved, we have some difficulties with that 24/7 issue and we certainly have difficulties with the numbers. The total numbers in Northern Ireland are around plus or minus 100 or 110.

Mr Dunne: Thanks, Chair. Thanks very much, panel.

Mr Beggs: Thank you for your presentation. We hear of the golden hour in general emergency treatment. How has that moved to the golden three or four hours? How are you setting a standard of three or four hours for children who are in such a vulnerable situation?

Dr M McCarthy: The two are not necessarily directly comparable. The golden hour that we have always known is about getting somebody to an A&E service quickly, and it tends to refer to accidents and trauma, etc. The standard of three hours for a child in an emergency — ideally it should happen within three hours but certainly within four — was drawn in the first instance from standards that were developed across the UK. It was then tightened up in our group, because, originally, we had a standard of four hours. We recognised, as came out in the consultation, that one document for England recommended three hours by road. Therefore, we tightened our standard.

It is worth recognising that, before being transferred, a number of children will be seen, treated and stabilised by cardiology staff. That is comparable to what happens before we transfer neonates. They are seen, treated and stabilised by the neonatologist and then transferred. So, that would play a key role in keeping the child stable.

The other thing to bear in mind is that, in an emergency, a number of those children will have a doctor or nurse with them to ensure that their circulation, etc, is maintained en route. So, it is somewhat different from the 999 ambulance call, where being able to access maternity or A&E within an hour is the standard that we aspire to.

Mr Beggs: Can we have clarity on what you are saying? Are you saying that the time is three to four hours from a decision being taken in Belfast? The mothers and children in need may be identified in Coleraine, Londonderry or Ballycastle. There will be a delay while they are transferred to Belfast and an assessment is carried out, and then there will be another three or four hours' delay. Can you confirm that that is what we are talking about?

Dr M McCarthy: The standard, as agreed by the entire working group, is that there are a number of people who require urgent treatment, but they can wait a day or two, and, in fact, they are well stabilised for a day or two. For those requiring immediate treatment — we considered "immediate" as being within hours — the totality of the patient journey time from the clinical decision to refer them and to their getting to the hospital site where definitive treatment will take place should be three hours and no longer than four hours. The entire group deemed that a reasonable standard. If you can get somebody to their definitive place quicker, of course, we will do that, and the one and a half hours that Dean cited is probably in the range of possibility for a child's being transferred from Belfast to Dublin. However, we were saying that all children should reach their definitive place of treatment within four hours and, ideally, within three hours.

Mr Beggs: Can you understand why some parents who have experienced a need for emergency treatment are concerned that that further delay will create additional risks for other children? Those parents have been through that situation. It is not necessarily about them; it is about other children. Do you not understand that they are concerned about the additional risks that will result?

Dr M McCarthy: I absolutely understand. Any parent who is told that their child, particularly if it is a newborn, needs surgery, they want something done immediately, and the quicker the better. I absolutely understand that. I can also understand that there will be an anxiety about leaving wherever their residence is or their home town to have treatment. However, we need to acknowledge that, at the minute, in Belfast, we are simply not able to provide a 24/7 service. When I checked a week or two ago, I saw that, since 1 December 2012, all our emergency cases were being transferred to Dublin. The current situation is that we are not operating on children in an emergency. They are being transferred safely to Dublin, they are being accepted by Dublin surgeons and they are being operated on very swiftly in Dublin.

Mr Beggs: Who took that decision?

Dr M McCarthy: That is a clinical decision driven by the necessity to get children treated within the time frame. We have such a small service, with a very small cohort of staff, so it is simply not possible, with the best will in the world. We have an excellent 24/7 cardiology service. We have enough cardiologists, and they are able to provide cover every minute of the day, 365 days a year. However, with such a small surgical service, it is simply not possible to do that.

Mr Beggs: Finally, have you taken on board the views of clinicians on the ground who have been treating the children and are highly regarded? There is a genuine concern that, once the surgery is lost, there is a huge risk of the whole service unravelling. Do you not accept that there is a huge risk of cardiology services deteriorating in the long term — it is a very specialist field — as well as other related specialties that are required to maintain the full service at the Royal Belfast Hospital for Sick Children?

Dr M McCarthy: We absolutely recognise that. In fact, many consultation responses cited exactly that. Moreover, the majority of clinicians who responded said that they were concerned that a change in surgery might result in the unintended consequence of changes in other services. However, the working group was of the view — the clinicians were party to this and discussed it in detail — that if we take appropriate steps, we can avoid that happening. Those appropriate steps are around enhancing what we have so that paediatric cardiology in particular remains an attractive area for people to work in and, importantly, around maintaining what we call the interventional skills, such as the cardiac catheterisation that paediatric cardiologists do. If we retain those skills by encouraging paediatric cardiologists to do those procedures in the unit of choice — in Dublin, in this scenario — we retain the skills and expertise and become a desirable place for people to continue to come to, because Belfast was always seen as a good place in which to work. We also need to acknowledge that there are areas of Belfast where paediatric cardiology has been at the forefront — for example, in the development of telemedicine — and colleagues across the UK look to us for advice, and have been doing so recently.

If we continue to develop and we retain the skills, we are confident that we can avoid that happening, but we need to keep an eye on it and be mindful. The last thing that we in the working group want to see happening, and it is fair to say that it is the last thing that clinicians want to see — is other services withering on the vine as a consequence. Proactive steps will help to ensure that that is not the case.

The Chairperson: Jackie, I have just a few questions for you. Heather, you can come in, but this is mainly for the Department. We have heard a lot about the 200 children, give or take, who currently use the service. Sorry, but I looked at the figures incorrectly — it is 110. We have heard that around 400 children is the benchmark. Who sets those standards?

Dr Livingston: The standard of 400 is what was agreed by the Safe and Sustainable review in England and supported by the various clinical royal colleges and associations. It is really based on the fact that, for surgeons to maintain their skills — this is not unique to paediatric cardiac surgery but is the case in many areas of surgery — clinicians agree that there should be a minimum number of procedures undertaken annually to keep their skill levels high, and that is around 100.

The Chairperson: So the Safe and Sustainable review in England set those standards?

Dr Livingston: Yes, but they are supported by the medical associations and are based on a widely held clinical view, across many specialties, that you need a minimum number of around 100.

The Chairperson: I appreciate that. What is the view of those in Scotland? Did they go with that level?

Mr Sullivan: Can I just clarify —

The Chairperson: No, let Heather finish, and then I will bring you in. What did Scotland say when that level was set?

Dr Livingston: I do not have the exact response from Scotland. Scotland's unit does just under 400, but the figure is much closer to that number. My understanding is that there are three surgeons doing over 300 procedures, so there is the notion of each clinician having a number to maintain their skills. You get to 400 by reason of needing a 24/7 service. To allow for cross-cover, four clinicians are generally needed. In some circumstances, it can be done with three. The 400 figure is not set in stone.

The Chairperson: OK. I will let Dean come in briefly.

Mr Sullivan: Heather is right about the gestation of some of these things and from where the 400 figure comes. It is important for the Committee to be aware that every member of the working group is signed on the standard of every service commissioned for Northern Ireland being of a standard that sees it work towards a performing a minimum of 400, and ideally 500, paediatric cardiac surgical procedures a year, consistent with —

The Chairperson: So where did that figure come from?

Mr Sullivan: From all the sources that Heather mentioned, but the key —

The Chairperson: But you are talking about an approach for here.

Mr Sullivan: Yes, and it was an approach for here that was agreed by all the members —

The Chairperson: By all the members of the working group, which was fair enough.

Mr Sullivan: — of the working group, Chair.

The Chairperson: If all the members of the working group signed up to that figure of 400 —

Mr Sullivan: Where is that derived from? Miriam may wish to add to that.

Dr M McCarthy: We in the working group discussed this quite extensively. It is fair to say that there was some concern that we might simply be embracing a standard that was developed elsewhere. However, when we teased it out, there were some core things on which every member of the working group agreed. The first was whether children should be looked after by a service that can provide 24/7 cover. Should somebody be there if something happens at 3.00 am? The 24/7 component was agreed, and fulfilling that requires a minimum number of people.

The other aspect that was agreed on by everybody was, as Heather indicated, is that there is a minimum number of procedures for every surgeon. We must remember that paediatric cardiac surgery is not a single procedure; there are hundreds of different procedures. The ideal is that anybody doing paediatric cardiac surgery should be doing 100 procedures a year, and ideally up to 150. Therefore, if you start with the premise that you want to provide care 24/7 and that an individual surgeon must do 100 or 150 procedures, you get to the point at which your minimum number of procedures to sustain the unit is in the region of 300 to 400, hence the wording. So —

The Chairperson: I understand all of that. We are the masters of our own destiny. If you are saying that members of the working group agreed on the figure of 400, and based on what you have just said, was there any other evidence to back up the figure of 400? That seemed to be used in England. Did we just lift it from there, or was there local evidence to back it up?

Mr Sullivan: It is not really the sort of thing that there would necessarily be evidence for either way. There is evidence in all sorts of areas, not just in paediatric cardiac surgery but in life in general, that the more that you do something, the better that you get at it. As Miriam said, by their nature, children present with different sorts of comorbidities and complicated conditions. Therefore, it does not seem unreasonable that you would need to be doing quite a lot of those procedures to keep up your skills. Best practice seems, as Miriam said, to be at least 100 and potentially as many as 150. That is where that number comes from. The accepted minimum standard of 24/7 cover cannot be delivered safely and sustainably with fewer than four staff, and the figure of 400 is simply the multiplication of one number by the other.

Mr Wells: A charity involved in the field contends that a person's heart does not change because he or she moves from being young to being an adolescent and then to being a 20-year-old. Why not give consultants and surgeons the skills that they need by bringing a wider age group into this particular unit. They will still do 100 procedures, but on one day they might be operating on a three-week-old baby and the next a 16-year-old. Some of the children have lifelong heart conditions and may require regular treatment. Why not just expand your horizons a bit to give your surgeons 100 procedures a year? I accept that they need to hone their skills, but why do some patients' requirements suddenly change after a birthday?

Dr M McCarthy: That is a very reasonable point to make. Actually, across the UK, adults with congenital heart disease tend to be operated on by the same surgeons who perform procedures on children, because the techniques are similar. Work is being done in the UK that looks at adults with congenital heart disease and what the standard should look like. That has been shared with the Belfast Trust and us, and we have the opportunity to comment on that. In the last year that we looked at, we were doing around 30 adults: there were roughly 110 children and 30 adults, which brings us up to about 140 procedures to be done in Belfast, so the numbers still fall far short.

Mr Wells: There are lots more people out there who need heart surgery — way beyond 30 adults. There is plenty of work out there for heart surgery.

Dr M McCarthy: We did procedures on only 30 adults with congenital heart surgery in the last complete year. The surgeons who perform paediatric cardiac surgery and do the adults who also have the paediatric problems tend to perform a very different kind of surgery to that for adults having a heart bypass, for example. The cardiac surgeons who do bypass surgery and replace valves, and so on, tend to be a different group of surgeons from those who do the paediatric surgery. Ten to 15 years ago, surgeons did a bit of both, but now those doing surgery on the congenital conditions, either in children or adults, tend to do only that kind of surgery and not other kinds. That is a professional change as the specialty has developed and as surgeons' skills have developed.

The Chairperson: Jackie, these are my final two questions, you will be glad to know. I heard the Minister being interviewed at the end of last week. I am paraphrasing what he said, but if I have picked it up right, he said that there were some weaknesses in the recommendation. However, during Question Time on Monday, he said:

"I am interested in continuing a discussion with my counterpart in the Republic of Ireland to identify whether, if the network is based in Dublin, there will be any ability to provide key surgical services in Belfast while enhancing provision on the cardiological side of the service." — [Official Report, Vol 84, No 5, p29, col 1].

He went on to say that he would:

"explore the scope for flexibility in the location for the future delivery of this service without compromising any aspect of patient safety." — [Official Report, Vol 84, No 5, p34, col 1].

What does that mean?

Mr Johnston: I think that he wants to explore the scope to see whether any surgery is possible in Belfast, because, obviously, there is a range of surgical procedures required. He will be looking at the entire scope to see whether there is any possibility of any surgery being continued.

The Chairperson: You and Heather are doing that work, so I take it that you are looking at all that.

Mr Johnston: We are advising the Minister on that, yes.

The Chairperson: He promised that he would keep us in the loop. Can you ensure that that happens?

Mr Johnston: We will do, yes.

The Chairperson: OK. On behalf of the Committee, thank you very much and thank you for your presentation.