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Assembly

Committee for Health, Social Services and Public Safety

OFFICIAL REPORT (Hansard)

Paediatric Congenital Cardiac Services: Departmental Briefing

22 October 2014

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Ms Maeve McLaughlin (Chairperson)
Ms Paula Bradley (Deputy Chairperson)
Mr Mickey Brady
Mrs Pam Cameron
Mrs Jo-Anne Dobson
Mr Gordon Dunne
Mr Kieran McCarthy
Ms Rosaleen McCorley
Mr Michael McGimpsey
Mr Fearghal McKinney
Mr George Robinson

Witnesses:

Mr Jackie Johnston	Department of Health, Social Services and Public Safety
Mr Ryan Wilson	Department of Health, Social Services and Public Safety
Dr Paddy Woods	Department of Health, Social Services and Public Safety

The Chairperson (Ms Maeve McLaughlin): Folks, you are very welcome to the meeting. From the Department of Health, Social Services and Public Safety (DHSSPS), we have Dr Paddy Woods, who is the Deputy Chief Medical Officer; Mr Jackie Johnston, who is the director of secondary care; and Mr Ryan Wilson, who is from secondary care. You know the format: you give an overview presentation on the recent statement, and we then open it up to members' questions.

Dr Paddy Woods (Department of Health, Social Services and Public Safety): I thank the Committee for the opportunity given to the Department today to brief members on the Minister's recent announcement concerning the recommendations of the international working group on a potential model for the delivery of congenital cardiac services to meet the respective needs of the population of Northern Ireland and the Republic of Ireland. As you said, Chair, I am joined by my colleagues Jackie Johnston, the director of secondary health care policy, and Ryan Wilson, who is a policy manager in the Department. You received the Minister's statement to the Assembly last week, the joint policy statement from Ministers Wells and Varadkar and the international working group's report. At this point, I do not intend to refer to these in any detail, but, by way of introduction, I will reiterate some of the Minister's key points.

The report has 14 recommendations, all of which are important. Indeed, the international working group stipulated that all the recommendations are interdependent. The Department believes that the overall package addresses the range of serious concerns that patients' families, patient groups and clinicians have made known in the conduct of this review and, indeed, previous reviews. The proposed solution provides for a surgical service that would see children being treated in accordance with the highest standards of quality. In implementing this new model, there will be a requirement to plan and to take it forward in stages as some elements will, by their nature, take longer to achieve than others. We know that the immediate concern of patients, their families and their clinicians is about what happens now and in the short term.

I assure the Committee that the Department has been working closely with the Health and Social Care Board (HSCB), the Belfast Health and Social Care Trust and colleagues in the Republic of Ireland to understand what a pathway to implementation may look like, what obstacles will need to be addressed and what investment may be needed along the way. In the meantime, and central to that, we assure you that everything possible will be done to have arrangements in place both now and for the foreseeable future to ensure that patients receive the best care available.

The Minister will ask the Health and Social Care Board to make detailed investment proposals to develop further a cardiological centre of excellence in the Belfast Trust and to strengthen the Northern Ireland cardiological network. This will involve working closely with the Belfast Trust's cardiologists and management in developing investment proposals to complement the international working group's proposed model.

With regard to the next steps, and subject to the Minister's approval, the Department will launch a public consultation document shortly, inviting views on the international working group's recommendations, which the Minister will consider before making his final decision on the implementation of the recommended model. In the meantime, the Department is progressing with planning for this as far as we can take it in advance of the Minister making a final decision, taking all necessary precautionary steps to ensure continuity of the service in the short and longer term.

That concludes my opening remarks, Chair, and my colleagues and I are now open to questions from the Committee.

The Chairperson (Ms Maeve McLaughlin): Thank you, Mr Woods, for that. The specific issue is the short term, particularly for families and charities. The capacity in Dublin involves an 18-month process, but Belfast will not be operational from January 2015. How will that gap be plugged?

Dr Woods: In the immediate short term, arrangements will be retained until the end of this calendar year. Service-level agreements (SLAs) are in place with Dublin for the provision of emergency surgery in Dublin and for surgeons from there to come to Belfast once or twice a month to undertake a number of cases. Arrangements and service-level agreements are in place with the Evelina hospital in London and Birmingham Children's Hospital. All those will and can be modified to accommodate the changes that will occur post January 2015 to allow for the continued attendance of all those groups of children. At present, those service-level agreements cover all children in Northern Ireland who require cardiac surgery. A modification of the SLAs will allow arrangements to continue to cover all children from Northern Ireland who require cardiac surgery.

The Chairperson (Ms Maeve McLaughlin): Are you saying that January may not be a cut-off point and that, until capacity in Dublin is resolved, the arrangements could be in place?

Dr Woods: It certainly marks the end of the current service-level agreement to allow surgeons from Dublin to come to Belfast to undertake operations. At this point, the indications are that that element of the service-level agreement will cease. As I outlined, a number of other service-level agreements could be modified to accommodate that change in the interim.

The Chairperson (Ms Maeve McLaughlin): I am mindful that there are individual cases in the middle of all this. I was informed today that only three places for surgery are left in the Clark clinic before Christmas.

Mr Jackie Johnston (Department of Health, Social Services and Public Safety): As Paddy said —

The Chairperson (Ms Maeve McLaughlin): Is that accurate?

Mr Johnston: There are two or three sessions before Christmas. The number of patients on the list for those sessions is determined by the clinicians. There will be at least a couple of sessions before the end of December.

The current service-level agreement with Dublin came into play in January this year. We have extended it twice: to the end of June, then to the end of September, and now to the end of December. There are ongoing discussions with Dublin to extend it to the end of March, which will allow the Dublin surgeons to continue to come to Belfast to provide cover for invasive catheterisation procedures. That work will continue in Belfast from January through to April, but no surgery will be carried out by those surgeons during that period. We will look at how we extend the SLAs further as we go through the 18-month implementation period.

SLAs are also in place with Birmingham and Evelina. Those will continue and will be extended as necessary in terms of demand in Belfast for patients from Northern Ireland and capacity in those centres. There will be a similar continuity of service to what you have seen since last year, the exception being that there will be no further surgery in Belfast from the end of December.

The Chairperson (Ms Maeve McLaughlin): To cut through this: people want a sense of those assurances. A huge amount of work has been done about getting the right model. We need to be mindful of the international opinion that we have been given. We also need to be very clear that we will not leave a gap in services. People need to hear assurances from the Department.

Mr Johnston: We can give a categorical assurance about that. There is a very close working relationship between our Health and Social Care Board and the Health Service Executive (HSE) in the South. There is a very close working relationship between clinicians in Belfast and clinicians in Dublin, Evelina and Birmingham. There are regular review and liaison meetings that involve the commissioners and providers. All that has been actively worked on over the past year or so, and that will be the case for the next 18 months. You can have that categorical assurance —

The Chairperson (Ms Maeve McLaughlin): — that there will be no gaps in services.

Mr Johnston: There will be no gaps in services; continuity will be maintained. If those centres have capacity issues, we have that series of SLAs to make sure that we have core SLAs and backup SLAs . If the centres have a surge of unexpected patients, we can bring alternatives into play as we need them.

The Chairperson (Ms Maeve McLaughlin): There are 14 recommendations. Recommendation 4 advocates the flow of nursing and physician personnel between what are called the two jurisdictions. Will you tease that out for me? How will that be advanced?

Dr Woods: A key premise behind the international working group's report is that the whole becomes greater than the sum of the parts. The Belfast unit has strengths, and the Dublin unit has strengths, and, to a certain extent, they are complementary. They have the capacity to deliver the surgery, and we have greater capacity in cardiology. Ultimately, the working group envisages an integrated service, so, from the point of view of patients, it really will not matter what part of the island they come from. The service that they receive will be identical in all respects, irrespective of where they receive it.

A key part of that, of course, is the interchange of staff, be that medical or nursing, to integrate the working practices between the two units and also to bring the strengths and expertise of one aspect of the service, whether North or South, to the other aspects. In some respects, our current SLA, whereby Dublin surgeons come up here, is an aspect of that. It will not be a future aspect, although surgeons will come north to provide outpatient facilities and follow-up to their surgery, but not the surgery itself.

The Chairperson (Ms Maeve McLaughlin): You talked about staff interchange. Are there any issues with the terms and conditions of employment contracts across the islands that might be an obstacle?

Dr Woods: The long-term employment relationship has to be worked out. As it stands, staff will be employed by their current employers. The issue is about being given leave to work in the other jurisdiction and being registered there if you are a registered practitioner, whether a doctor or a nurse. However, in the short term or the long term, none of those issues is insurmountable.

The Chairperson (Ms Maeve McLaughlin): You said that there are issues that will have to be worked out. Who works those out?

Dr Woods: Ultimately, that will be for the respective employing organisations: in our case, largely the Belfast Trust and, in the South, Our Lady's Children's Hospital, Crumlin. Again, as the international working group recognised, there is, first and foremost, the will, at clinician and employer level and, as expressed by the two Ministers, at the political level, to bring that about. As I see it, that is vital in unlocking those issues.

The Chairperson (Ms Maeve McLaughlin): Health is also an area of cooperation so you would assume that tool would be utilised, but you say that those issues are not insurmountable.

Dr Woods: I do not see them as insurmountable.

The Chairperson (Ms Maeve McLaughlin): Recommendation 2 advocates the establishment of the family advisory group, and the Minister went to great lengths to talk about how that will feed into governance delivery. How are charities or families appointed or nominated to those groups, and how will they participate?

Mr Johnston: In the past, we involved the two main patient groups — Heartbeat Northern Ireland and the Children's Heartbeat Trust — in the work that was done, for example, by the PCCS working group. Both charities had nominated representatives on the working group, so it is not unusual to involve them. Other clinical networks in Northern Ireland have patient representatives. The international working group's report identified specific individuals who should be represented on the proposed clinical network, for example, and on the family liaison group. We want to talk to the charities to seek their views on how they want to nominate their representatives for those groups.

The Chairperson (Ms Maeve McLaughlin): Is there not yet an agreed template for that or an agreed way forward?

Mr Johnston: The usual way is to contact them and say that we would like them to become involved in specific work or a working group, and we ask them to nominate a representative to come on board. We did it recently, for example, with the rare diseases plan for Northern Ireland, which the Minister will publish next week. The local rare diseases partnership group had a representative on the working group for that. We have a process for doing that.

The Chairperson (Ms Maeve McLaughlin): I suggest that what was advocated in the statement is slightly different, and it put great emphasis on the need for families' voices in the process. If we have learned anything from looking at the Boston model, it is that that was critical to how the service was delivered. I do not think that the same old process will do; it has to be something new.

Mr Johnston: That is specific to the family liaison group, where you would have a wider forum for the families to speak collectively and individually to the network that we want to set up. That is a new dimension that the working group has proposed.

The Chairperson (Ms Maeve McLaughlin): If a family or a charity wants to be involved in a conversation process, how do they do that?

Mr Johnston: Do you mean in terms of the liaison group?

The Chairperson (Ms Maeve McLaughlin): In terms of what is said in recommendation 2 about the family advisory group. Recommendation 8 also supports patient and family services.

Mr Johnston: We have not worked out the detail of how that group will operate, but we will talk to the family groups that are currently constituted and ask for their views on how they would want it set up and how they would want the families involved in it. I imagine that a similar process will happen in the South and that their families will be asked. We will invite the families' views; we will not tell them how we think it should be done.

The Chairperson (Ms Maeve McLaughlin): OK. Can we be kept informed?

Mr Johnston: Yes, very much so.

Mrs Dobson: Thank you for your briefing. You are aware that this is an issue that I have been very involved in. I have stood shoulder-to-shoulder with the parents over this period and have listened to their very real fears. As you know, their hopes have been lifted and then dashed again.

You are also aware of the response that the Minister made in the Adjournment debate that I brought to the House last Tuesday night. I do not think that we have a copy of that in our packs, but let me quote you from the Minister's response:

> *"the entire island of Ireland has just about enough procedures for a safe and sustainable service. My difficulty ... is that I have had four separate reports by four separate bodies telling me that this is not safe." — [Official Report, Vol 98, No 4, p83, col 2].*

If that is the case and the Minister is convinced that Dublin is the solution, families ask me this: what is the point of further consultation if his mind is already made up? Will you clarify that for them?

Mr Johnston: There are 14 recommendations in the working group's report, so each of those will be consulted on. If the families, stakeholders or general public have specific ideas about how the recommendations can be refined, improved or moved forward, the Minister wants to hear them. Similarly, the Chair referred to how the family liaison group will work, and we want to hear views on that before we actually finalise it. It is really giving everybody an opportunity to say, "Here are the 14 recommendations; how do you want to see them implemented? What are your views on them?".

Mrs Dobson: Is that unlikely to change the outcome?

Mr Johnston: The Minister has not finally made his mind up on this. He will listen to the outcome of the consultation, and then he will make his mind up. As a precautionary measure, however, as Paddy was saying, because we need to have the continuity of the service in mind, we are planning as much as we can in advance of the Minister making that final decision. However, he still has to take the final decision.

Mrs Dobson: OK. That is a concern; there is a fear that it is a consultation that is meant to be seen to be consulting when the decision has already been made.

Another point is that, when I asked the Minister about the capacity of the Northern Ireland service — if I may quote him again, Jackie — he said that the:

> *"demographers tell us that Northern Ireland will never have a sufficient number of children to guarantee that the service would be sustainable and would attract clinicians." — [Official Report, Vol 98, No 4, p84, col 1].*

Can you give us the background to why this service operated in perfect safety in Northern Ireland for so many years without concerns being raised?

Dr Woods: I guess that there has been a generational change over the last five or six years in that the surgical element of this service resided with an individual. Since his retirement some years ago, various arrangements have been put in place to maintain the service in a safe but not sustainable way. The arrangement has been for a relatively young surgeon to be supervised and mentored by an experienced surgeon who was at or near retirement and who has subsequently retired. There have been ongoing attempts to recruit to the service, but none has had success. Again, that is part of it.

We serve a population of 1·8 million, we have some 350,000 children under 16 years of age, and we have 25,000 births each year. The incidence, in aggregate, of these conditions — a range of conditions give rise to congenital heart disease — is between eight and 10 per thousand births, and only half those individuals will require surgery at any point in their lifetime. So, the numbers who will require surgery for congenital heart disease are relatively small. We can anticipate approximately 200 a year; I think that the figures over recent years have been about 150 surgical procedures per year.

Whilst it is open to debate how many cases a surgeon needs to undertake to maintain their proficiency and skills in any procedure, aside from this group of procedures, once an institution stops operating on fewer than 200 cases per year, there is evidence for less-optimal outcomes from that surgery. So, that is a significant issue.

Whilst in the past a lot of services resided in individuals effectively making themselves available 365 days a year, 24 hours a day, as Dennis Gladstone did, that position has become less tenable. It is not a good position to be in from a safety point of view anyway. It is a recipe for burnout, error and people leaving.

The generation coming up will not provide that type of service and, indeed, should not be asked to, in that, ultimately, the demands placed on individuals in those circumstances are far from reasonable. Belfast has consistently struggled to recruit a single surgeon, let alone a team that would allow sufficient numbers to provide a 24/7, 365-day service and time off for leave, study to keep up to date and other activities that are absolutely germane to being a competent medical practitioner.

So, it is a culmination of the number of cases that Northern Ireland, given its population, can generate — it is limited to fewer than 200 per year — and the need not to have individuals providing a service, because we need it every day all year round, so we need a number of clinicians together. Again, the number of cases that they would attend to would also fall. So, it is a combination of those factors, and whilst historically they did not apply, they very much apply now in the modern era.

Mrs Dobson: Essentially, what I am gathering from you is that the service operated safely for all those years due to the commitment and dedication of the surgeon who was available 365 days a year.

Dr Woods: Yes.

Mrs Dobson: Can you give us a guarantee that the Mayer proposals have once and for all put an end to the notion that future provision of paediatric surgery for our children should go to England?

Dr Woods: That is both Ministers' commitment, yes.

Mr McKinney: The report is to be welcomed. I think that we are all acutely aware of the stressful circumstances that parents and families find themselves in with all these conditions. I am reminded of the words of the Heartbeat Trust and, indeed, of our colleague Robin Swann when he said that we would like to have this service in Belfast on our doorstep but that, given the demographics and expertise etc, the best option is this all-island solution.

On the day of the announcement in the Chamber, I think that the Minister nodded towards the proposition that elements of the recommendations could be furthered, even while the consultation was taking place. Have you had any further consideration of that?

Mr Johnston: That is what the planning concerns. We are, on a precautionary basis, going ahead and doing as much planning as we can in advance of the Minister making his final decision. For example, we are going to be working with colleagues in Dublin on a draft implementation/action plan. As you know, the two Ministers asked for that by December. It will be a fairly detailed plan, and we are progressing it.

I think that you referred to the possibility of a governance committee. We have in Northern Ireland a Together for Short Lives group working with us that brings together clinicians, the managers from the Belfast trust and the commissioners. So, there is an embryonic version of that committee already in Northern Ireland. I think that we will be working to see whether we can then begin to develop links with the South on this. Those will not be totally formal, because we need to make sure that the Minister has time to make his decision, but we will certainly do as much of that as we can so that we are in a good position to move forward quickly once that final decision is taken. So, we can give you the assurance that we are working on all that to try to progress it as far as we can.

Mr McKinney: There are elements that maybe could be furthered with or without this decision — or even outwith this decision. I mean things like transport, which would be needed, and telecoms. Those are things that should be furthered in any case.

Mr Johnston: Sure. The implementation plan will contain what actions are required to do that. In the context of providing enhanced services for the families, the Belfast Trust has been doing some work already on that. Ryan, I think that you have some details on the office that it has established.

Mr Ryan Wilson (Department of Health, Social Services and Public Safety): The Belfast Trust has confirmed that, following its engagement with parents earlier this year and the focus groups that it had involving the Health and Social Care Board, it has opened a patient experience office in the Royal Belfast Hospital for Sick Children, with a member of staff dedicated to looking after the needs of families, particularly those who have to travel outside Northern Ireland for treatment. That gives them a point of contact directly in the hospital while still keeping the travel office that operates from the Health and Social Care Board for patients in general who have to travel outside the country.

Mr Johnston: As we move forward, that development can be bolted on to what will be the all-island model. So, we have bits of the jigsaw already beginning to emerge.

Mr McKinney: Furthering the Chair's point, you talked about involving the families to a certain level. Is there a greater level to which they could have input now, given the reassurance, if you like, that this model should be the most robust for them and others who are going to go on and suffer?

Mr Johnston: They will have full participation on whatever governance board is set up. They will be full members of that, except in the case of clinical decisions, because, obviously, those are for clinicians to take. We want to hear the views of the family liaison forum on how it wants to give its input. So, as far as we are concerned, how the families want to be involved is an open door.

Mr McKinney: Are you leaving the door open, or are you actively seeking their views?

Mr Johnston: We will be actively seeking their views. Obviously, we are just working on all this stuff at the moment, but, over the next few months, we will be seeking their active involvement in developing the plans.

Mr McKinney: Importantly, the report did not touch on cost at all, but have you done a cost analysis of it all?

Mr Johnston: The current cost of running the surgical side of the service, for example, is approximately £3·5 million per annum. That is just for the paediatric end of the surgical side. In addition, Ryan has the figure for the cost of the air ambulance for transferring to England.

Mr R Wilson: The total cost per annum is in the region of £2 million. There are between 300 and 400 cases per year that use the air transfer service at a cost of approximately £6,000 a case.

Mr Johnston: Not all those are paediatric patients. So, the current recurrent cost is our starting point for looking at how that is invested in the all-island model, as it were. Last year, there was indication from the board that it gave a commitment that there would be investment in modernising the cardiology side of the service in Northern Ireland. I think that £1 million was indicated at that time, subject to business case, etc. Again, that is available. Because we are looking now at an all-island model, we need to take those figures to the table along with the figures from our colleagues in the South to see how we fund that model in total.

Mr McKinney: Forgive me if I am naive about these sorts of things, but what sort of ratio is it? Is it a 50:50 ratio? Is it based on population ratios?

Mr Johnston: The detail of that has to be worked out; we have not worked out the detail at the moment. The one that I am most familiar with is the radiotherapy centre for Altnagelvin, where, as you know, the South made a contribution on the basis of population usage. It cost about £70 million, of which they gave about €17 million or €18 million. They are then paying per patient, as it were, for treatment at that centre under a service-level agreement. So, we have broad processes that we have already worked in to develop that kind of cost. We will work through that detail, and we can come back to the Committee and share that with you. That is detail that we need to get moving on.

Mr McKinney: As you look at it now, are you seeing that this will cost more, simply, or that it will cost less and bring a saving?

Mr Johnston: I cannot give you a direct answer to that because we need to do the thorough analysis of it. Given that there is a cost in transporting patients over to England, for example, and a lower cost in transferring patients to Dublin, that indicates that there will be a saving at that end of it. Hopefully, that will be reinvested.

Mr McKinney: You will come back and report on those.

Mr Johnston: As we go forward over the next 18 months, we will come back and give you further briefings as you require.

Mr Dunne: Thanks very much, gentlemen, for coming in this afternoon. We all recognise the excellent work that is being done in the Clark clinic and the Royal Belfast Hospital for Sick Children. Can you give us an assurance that services there for young children and babies prior to and after operation will be retained?

Dr Woods: We can give a categorical assurance that the cardiological service in Northern Ireland will be retained and primarily based at Clark clinic. Indeed, in line with the international working group's recommendation was that investment was needed here and in the Republic of Ireland. So, I can give a categorical assurance on that, yes.

Mr Dunne: So, we are going to see an enhanced service there.

Mr Johnston: Yes. The Minister met the cardiologists last week at the children's clinic. He asked them to bring forward their detailed proposals. They did submit proposals last year to the previous Minister on how they see the service developing along the lines that you are suggesting. He has asked them to have another look at that out of the working group's report, so we will have that bit of work from the cardiologists and from the board before the Minister makes his final decision again. That will be available to him. They are talking about, for example, investment in clinical rooms, and I think that there is a particular medical discipline that they are looking for.

Dr Woods: That is clinical physiological staff. As Mr McKinney said, tele-links to some of our peripheral units such as Altnagelvin —

Mr Dunne: So, there will be a centre of excellence.

Dr Woods: That is the intention.

Mr Dunne: That is the plan. That is good.

I have a couple of other points. At present, certain children travel to England for their operations. Can you clarify the position from January onwards for children? Will they still be required to go to England for some time until Dublin is established? Is that what is proposed?

Dr Woods: In broad terms, yes. It is recognised that the capacity is not present in Crumlin at this time. We expect, as part of the development of the service over the next 18 months, that, incrementally, the capacity in Crumlin will increase. As that happens, an increasing number of children from Northern Ireland will receive their surgery in Crumlin. In the immediate future, the likelihood is that more will receive their surgery in centres in England, primarily.

Mr Dunne: Initially.

Dr Woods: Yes, but for as short a period as is possible or is feasible with the increase in capacity in Crumlin.

Mr Dunne: Is a new hospital planned for Dublin?

Dr Woods: There is.

Mr Dunne: Is that what we are waiting on to have the sufficient capacity?

Dr Woods: Again, the joint statement says that the end point of that is the new children's hospital in Dublin, but the developments that are envisaged as a result of this report will take place in any case.

Mr Dunne: Will they?

Dr Woods: Yes.

Mr Dunne: We will have the capacity.

Dr Woods: Yes, the investment from both jurisdictions will secure that.

Mr Johnston: The working group has given an indication in the report of the capacity. For example, it is indicated that 10 additional intensive care unit beds will be required. A fourth surgeon and other staffing developments will be required. There is a route map in there that the international working group has given on what, in its view, is required for capacity for the entire island. We have got that. It is not only about the physical bit but about the beds and the staff to provide the service for those beds.

Mr Dunne: At present, children are treated in England, and, obviously, some go to Dublin. Is that correct?

Dr Woods: That is right.

Mr Dunne: I remember that, roughly three years ago, when we all got elected, this was one of the main issues that came on the agenda. I remember attending a public meeting in Bangor, and one of the first people who got up said that their child had been to Dublin and had had the operation, and they were very satisfied and acknowledged the excellent skills and service that were provided. So, we have had that for some time. How long has it been the case that children have been going to Dublin?

Dr Woods: We have records going back over four or five years.

Mr Dunne: There is also the swapping of consultants and surgeons between Belfast and Dublin. Has that been going on for some time?

Dr Woods: For the most part, surgeons have been coming north to undertake surgery. In reality, we have not had the surgeons to go south for a number of years.

Mr Dunne: You have not. So, the bottom line is that this issue is about establishing and maintaining skills. Is it really about the cost?

Mr Johnston: No. There is no cost issue involved.

Mr Dunne: Effectively, this could prove to be more expensive than the present arrangement.

Dr Woods: There is that possibility. Again, I refer you to the joint statement, where there is a commitment from both Ministers to implement the proposals as quickly as possible and a recognition, as the report makes quite clear, of the need for investment either side of the border. So that is a commitment, and it is a possibility, yes.

Mr Dunne: The bottom line is that we want an assurance that we are getting a high-quality service at the end of the day. Are you giving us an assurance that that will be the case? Will the children now be assured of a high level of service?

Dr Woods: Certainly, the vision painted in this report gives every indication that that will be the case. In addition, we have the evidence from our families and patients, who are using the service currently and who have had a less than optimal patient experience in having to travel to England for surgery. That has to be accepted, and it is all part and parcel of a high-quality service. I do not think that you need to be a doctor or a great scientist to understand that a journey of 100 miles down the road — if you live in the north-west, 160 miles down the road — is preferable to all the stress and upset of going to the international airport, getting into a plane and going to unfamiliar places, possibly with no or limited family support for a period. In some instances, that stress can be quite extensive. That, in itself, is worth investing in.

Mr Dunne: You are giving us an assurance that the quality of service that children get by travelling, as they do at the moment to England and to Dublin, will certainly be maintained.

Mr Johnston: There are two bits involved. On the clinical side of it, there is a national cardiac audit database. Paddy can give you a bit more information on that. It looks at the clinical outcomes. Belfast and all the other heart centres in the UK contribute to that database, and Crumlin has also been contributing since last year. So, we will know whether the outcomes are of the quality that you are indicating.

The other side of it is the family support. One of the very positive things about the working group's report is that, for the first time, it is going to empower the families in a way in which they have not been empowered in the past, in dealing with the issues that Paddy alluded to. If you have two or three young children at home already, you need support to make sure that you can sustain family and working life etc. All of those issues can now be given more of a voice than they have had in the past. So, not only do you get continuing quality of service on the clinical side; on the family support side, there will also be improvements if we get the full implementation of this model that the working group has suggested.

Mr McCarthy: Thanks very much for your presentation. Gordon relayed the good experience that someone had in Dublin. I can say to the Committee that I have a constituent who had the opposite experience in having to travel to England. That concurs with what you have said. The fact that you have to go and look for an aircraft and all the rest of it and you have no family backup is not good. We do not want that. Whilst we are all extremely disappointed that the statement was made that Belfast is losing out on this, nevertheless, it is going to Dublin and we look forward to the first-class service that, I am sure, we will get and are entitled to.

My question is about the commitment to and timescale for the new arrangements. You have both given us a good commitment on where we are going from here, which is very welcome. The public consultation is not even out yet, and we do not know when that will be. Could you have a stab at the new arrangements? When will we see the conclusion, which we all want to see?

Before I stop, Chair, I express my congratulations and thanks to the people of the Royal Victoria Hospital and the Clark clinic. We visited it, and the work was enormous. It was fantastic to see the lives that have been saved there. It is a pity that it is being taken away. Nevertheless, I put on record our thanks to all the staff up there for the work that they have done.

I am looking for information on the consultation and the arrangements thereafter.

Mr Johnston: Subject to the Minister approving the consultation document, we hope to have it out before the end of the month, which means next week. We are working on that at the moment, and we will try to get it out quickly because we want to have it concluded by January in terms of people having an opportunity to have their say.

Regarding the implementation, there has been mention of 12 to 18 months. That is really just an estimated time, at the moment, of how long it will take to implement the full model. We are building from a very strong base. As I said, a strong, close working relationship has been established over the last year or 18 months between our board, the Health Service Executive in the South, and clinicians in Crumlin and Belfast. That is a really good base to work from. Those people know one another. They have been working closely in the interim arrangements, so the relationships have been established. It is really about the Departments getting the structures in place to allow the clinicians and commissioners to make progress as rapidly as they can.

You asked me whether we are in a position to move forward quickly. The essential building blocks are all in place. It is really just a matter of moving forward as quickly as we can once the Minister takes his final decision.

Mr McCarthy: The consultation will be completed by —

Mr Johnston: January.

Mr McCarthy: So, could there be a decision after that?

Mr Johnston: Yes, as soon as possible after that.

Mr McCarthy: I want to reiterate what other members said. I think that it was Jo-Anne who said that we hope that the Minister will acknowledge what comes out of the consultation, and, as somebody said, that the decision will not be made because it is the cheaper option. We want to make sure that it is the best for what we are after.

Mr Johnston: I will add a further point about the service in Belfast. We have a tremendous asset in the Clark clinic, which, I think, everybody recognises. There is no question of that being reduced in any way; it is actually about enhancing and developing that service. The Minister has given a commitment on that. He has had a meeting with the cardiologists already. There will be detailed plans coming forward as to how we can develop that further and sustain it in the new model.

Mr McCarthy: That is very good news. I recall that, after the statement was made, the Clark clinic staff were worried about the future for them, but that has given us a good commitment to move forward.

Mr Brady: Thanks for the presentation. On the consultation, I presume that work will be done with groups and organisations to ensure that they partake. Reading the Minister's statement, it looks as if it is a fait accompli.

Mr Johnston: We will have a few outreach meetings.

Mr Brady: We are cynical, and most of us feel that about most consultations anyhow, but that is a different issue.

In terms of the logistics of the here and now, and without individualising a case, I was contacted by a parent yesterday whose child had scans and all in July. They were told that they would be operated on within three months, but they have now been told six months. While all this is going on, there are still cases. There is a worry that this is almost detracting from the urgency of cases that need to be dealt with now, whether in Dublin, Belfast or wherever. That is a real worry. That seemed to be the message that I was getting; the parent was very happy that all this was being sorted out, but their child needs to be dealt with now. Unfortunately, in that case, that does not appear to be happening.

Dr Woods: We are all very conscious that children will still be presenting to the services daily. In our engagements with the clinicians, they told us that they have now been operating in an area of uncertainty for more than two years. If nothing else, this provides certainty on the medium to long term. The work that we are getting into now will absolutely copper-fasten what happens in the interim, or certainly after 1 January 2015, so that families are not placed in that dilemma and the clinicians attending them know what the arrangements will be for them as and when they require them.

Mr Brady: I think that the worry for people is that urgency is required pre-Christmas. The major issues are going on, but the individual issues are maybe not being dealt with as they should be.

Dr Woods: If there is an issue pre-Christmas, arrangements are already in place to deal with all eventualities. That issue should be capable of being handled as things stand.

Mr McGimpsey: Thanks, Paddy and Jackie, for your presentation. This is, of course, an issue that I grappled with in my day. I had a somewhat different solution through a proposal that was handled for me by, I think, Dr McCarthy, but I will come to that in a minute.

You talk about the needs of Northern Ireland and the Republic of Ireland. Was your review of the needs of Northern Ireland? The statement refers to:

> *"Cardiac Surgery and Interventional Cardiology service for Congenital Heart Disease to meet the respective needs of the Republic of Ireland (ROI) and Northern Ireland (NI)."*

Was this a review of an all-Ireland or Northern Ireland solution?

Mr Johnston: The background is that, in 2012, the previous Minister asked the Health and Social Care Board to carry out a review of the configuration of the future service for the needs of Northern Ireland only. That report came in in April last year. It recommended, for the reasons that Paddy referred to earlier, that surgery should end in Belfast and be carried out in Dublin. The previous Minister was not content with that and said that he wanted to see whether it would be possible to have a model with a two-centre surgical solution, with one centre in Belfast and another in Dublin working together. So, the terms of reference for the international working group were to come up with a model that would meet the respective needs of both jurisdictions. In other words, what would be the best model to meet an all-island service but with regard to the particular needs of Northern Ireland and the Republic of Ireland.

Mr McGimpsey: So, the review was asked to look for an all-Ireland model, and you got one.

Mr Johnston: Yes.

Mr McGimpsey: When I was there, we looked at twin-track surgery in Belfast and Dublin. I understood that that was the resolution of this. What happened to that?

Mr Johnston: That is what Minister Poots was aiming for when he asked whether it would be possible to do that. What happened was that the number of children on the entire island would not provide for a two-surgical-centre solution. At the most, you have about 500 to 600 children in total. If you were to split them in whatever way possible, you would not have enough to sustain two centres, one in Belfast and one in Dublin.

Mr McGimpsey: OK. It is the centre in Belfast that I am primarily concerned with and that was my responsibility as Health Minister. You talked about optimal numbers and said that throughput for surgery in Belfast was 200. Is that right?

Mr Johnston: One hundred and fifty surgical procedures.

Mr McGimpsey: One hundred and fifty — and what do you say is the optimum safety limit?

Mr Johnston: The evidence indicates 400 to 500, with four surgeons each carrying out 100 to 125 procedures annually, as well as 24/7 emergency cover, which, again, needs to be provided by up to four surgeons.

Mr McGimpsey: As Jo-Anne said, we had Dennis Gladstone in there, and he provided the service, which was a second-to-none service. I understand that a single-handed service is difficult, which is why we looked at the twin-track model. That allowed time off for leave, study and all the rest of it, when you could lean on Dublin, but, similarly, Dublin could lean on Belfast. That provided surgery in two centres, and you have gone off that.

What I keep hearing is that the optimal number is not safe. I cannot see how that gels with Dennis Gladstone, who provided a fabulous service. You are suggesting that, given the numbers that he was dealing with, his service was not as safe as it was. I can tell you that that never raised its head when I was sitting in the chair. Where did the new safety number come from? If you have a safety number that you cannot hit, your answer becomes inevitable.

Dr Woods: Certainly, a number of professional bodies, such as the British Congenital Cardiac Association and the British Cardiovascular Society have supported that as a reasonable number for a surgeon. As I said in response to an earlier question, there are two elements at play here, some of which did not apply to the same extent in Dennis Gladstone's time. These standards were not in place, and they certainly were not as explicit as they are now. Now that they are explicit, you have to give them due regard. People then were not bound by things like the working time directive and whatnot. I would argue —

Mr McGimpsey: This is why we needed a twin-track approach. It is why Belfast cannot be stand-alone; Belfast and Dublin must work together.

Dr Woods: Also, you have to —

Mr McGimpsey: However, you have taken the next jump; you have moved surgery out of Belfast. I am not saying that that is the wrong move or anything like that. I will consider this during the consultation process, but it is not the advice that I got from the Department at that time.

Mr Johnston: As Paddy was saying, over the last four or five years, the body of evidence has developed around all this, both nationally and internationally. We are looking to a new scenario in professional opinion on this.

Mr McGimpsey: I was Minister only three and a half years ago.

Dr Woods: In the interim, there have been reports that have come to the same broad conclusion on the basis of that. Like you, your successor was very keen to explore — one might argue, to exhaustion — the potential for keeping two surgical centres on the island of Ireland. If memory serves me right, he gave that commitment to the Assembly in a debate last spring.

Mr McGimpsey: OK. We will leave that issue, which concerns me.

The next issue is that you talk about keeping the skills in Belfast, but, if the surgery is all moving to Dublin, how will you keep the theatre staff in Belfast? What will happen to them? Those folks — the theatre staff — are almost as highly skilled as the surgeon and the anaesthetist. They are very well trained. There is an expertise there that is second to none and that you could not build in a hurry. What will happen to those folks and their skills?

Dr Woods: You mentioned the anaesthetist and whatnot. Part of the interchange of personnel would involve them. The other part of the relevant recommendation, which recommended the cessation of children's surgery in Belfast, also recommended that the adult congenital surgery in Northern Ireland, based in Belfast, should expand and consolidate. There will be plenty of opportunity for that —

Mr McGimpsey: Is that not a different discipline?

Dr Woods: No, it is a related discipline, because —

Mr McGimpsey: If I went into the theatre and spoke to the theatre staff, would they say that it is the same? The message that I always got in children's hospitals was that it was very specialised. I just wonder what will happen. You are saying that their future is in heart surgery but for adults not for children. We talking about babies here.

Dr Woods: While we have a fairly static number of children with congenital cardiac conditions, by virtue of the success of people like Dennis Gladstone and his colleagues, we have a growing number of adults with congenital cardiac conditions. The anatomy of congenital cardiac conditions in children is quite different from that in adults.

Mr McGimpsey: OK. They will leave this avenue of surgery and move to another. Tell me this — you know it better than I do; you are a doctor — the other highly skilled staff that we have in there are the folks in intensive care and post-op. Again, there are levels of skill there that are second to none. What will happen to those skills and to those people?

Dr Woods: Again, the demand for intensive care generally is no less than that for children. A key part of the analysis of the international working group and other bodies was that demand will not be diminished so critically that their skills will —

Mr McGimpsey: They are parallel skills, but they are not precisely the same. They have provided such a fabulous service for us over the years, in theatre, recovery, intensive care and so on. It just seems that we need to have due care and attention as to how we look after those folks, not least because their skills are huge. I will have more to say in due course in other places.

We had the Fearghal question about the costs. You mentioned £3·5 million, but you said that there are also air costs because you are transferring people to England, which costs about £2 million, and all the rest that we may or may not save. Why do you not just transfer them to Dublin now, if you have £3·5 million and there is your service? What is it going to cost? What is our share of the cost of Dublin? You are hoping for a new children's hospital in Dublin, but we are due a new one in Belfast, is that not right?

Dr Woods: Yes.

Mr McGimpsey: All this could be part of that. I come from the approach that we provide a health service free at the point of delivery, and that it is for those in distress, pain and need. It is hard to think of anybody more in pain, distress and need than a baby who needs surgical intervention and their mum and dad. It is about looking to provide the best service we can. The patient outcome comes first, but it needs to be as close as possible. It seemed to me that we had a solution. That was only three and a half years ago. You have a different solution here. It comes back to the almighty dollar. You picked an individual — probably a genius guy — from Boston who did this, but he comes from a system where the patient follows the money. We have a system where the money follows the patient. How big a factor is the cost in this? If you are operating a system now that is £3·5 million, what are you going to be paying to operate the system on an all-Ireland basis? Somebody has done that sum.

Mr Johnston: We have to do the detail on the case mix etc. At the moment, not a huge number of cases go to Dublin; more go to England. To answer the first part of your question about why we do not do it now, it is because the capacity is not available in Crumlin at the moment to take all the cases, so —

Mr McGimpsey: It takes us back to where we started.

Mr Johnston: We have to build it up over the next year and a half. We will come back to you with the detailed costings.

Mr McGimpsey: If you can build it in Dublin, you could build it in Belfast.

Mrs Cameron: Thank you for your presentation. My question follows on from Michael's. You talked in your presentation about detailed investment to create the centre of excellence. Can you give us more detail on what that investment will be and any time frames? What are we relying on to make this all happen, so that the centre of excellence is up and running?

Mr Johnston: We cannot give you the detail at the moment because it is being worked up. It will include the timescales as well. It will be complementary to the all-island model recommended by the international working group. We see it being developed alongside the implementation of the all-island surgical service, which has been recommended by the working group. As the Minister said, he and Minister Varadkar have asked for a detailed implementation plan and action plan by later this year. That will be available.

Mrs Cameron: In relation to recommendation 8, can you give us some detail about what will be done to enhance the experience of and provide support for parents while they are in Dublin?

Mr Johnston: At the moment, the main concern that parents have is around accommodation facilities and what allowances are made available to them. Obviously, with a greater number of children likely to go to Dublin in the longer term, they will want to have a say about what is developed to accommodate that greater number of families. At the centre of the enhancement is the scale that is needed, what exactly the parents require and then what we can provide within our resources to make that as feasible and effective as possible.

Mrs Cameron: Will there be a guarantee that accommodation will be made available to them?

Mr Johnston: Yes, accommodation will be made available according to their particular needs. As I said, however, we have to work through the detail of that as well.

The Chairperson (Ms Maeve McLaughlin): The phones are interfering with the recording equipment. People should be mindful that phones should be switched off. There may be gaps in the recording today.

Ms McCorley: Thanks for the presentation. I will ask about other services and other types of medical conditions. Do you foresee more of this type of development, where you will look at how to best provide on an all-island basis rather than in a North/South way?

Dr Woods: In general terms, we can answer yes to that. It comes back to what was said in some of the introductory remarks: given the size of our population and the advances in technology and medical expertise to treat increasingly rare and complex conditions, I suspect that there is an inevitability about that. Ultimately, there will be, and there already are, conditions that a population of 5 million or 6 million cannot sustain or deal with. Some of the subsets of children with congenital cardiac conditions will continue to be treated off the island of Ireland, as they are presently, simply because of the complexity or rarity of their condition. So, yes, there is the potential for that to be more widespread.

Ms McCorley: What illnesses might be in that category?

Dr Woods: One that springs to mind is children's gastroenterological conditions, such as children with Crohn's disease and children with ulcerative colitis and suchlike. Again, those are relatively small in number. It is not such an issue on the surgical side because we have paediatric surgeons who can deal with gastroenterological conditions in the round, but there will be variants that are difficult to provide for locally.

Ms McCorley: Is it mainly children's conditions, or is it across the board?

Dr Woods: Ultimately, it is the rarity of the condition. We have a population of 1·8 million, but we have 350,000 children under 16 years of age, so you get into the law of diminishing returns.

Ms McCorley: In terms of provision, is it mostly about the numbers of patients, or is it about the standard of services that exist? Could you envisage a situation where all cancer treatments, for instance, are dealt with in one place? Of course, there are all different types of cancer, but might there be specific cancer treatments that could be located here?

Dr Woods: It is difficult to generalise. As you quite rightly say, cancer is not one condition. For the most part, cancers are diseases of ageing. With an ageing population, we can anticipate a growing number of some cancers rather than a diminution. However, there are cancers that affect the young, and there are exceedingly rare cancers. For the most part, we can manage conditions of cancer to the highest quality standards locally, but there will be exceptions to that, of course.

Mr G Robinson: Thanks to the team for the excellent presentation. I have several points. First and foremost, as someone who was treated in the Royal about 10 years ago for heart problems, I have nothing but the highest praise for that hospital. The work that it does is incredible from a heart point of view. I would not be here if it had not have been for the Royal. The treatment I got was absolutely excellent.

I will move on. Will children born with severe heart defects in, say, Altnagelvin be transferred to Belfast, or will they go straight to Dublin at present or in the future?

Dr Woods: In all truth, it is very difficult to generalise. How best an individual child is treated and where they are treated will be very dependent on the individual details of that child's case. That, ultimately, will be down to an expert assessment. We will continue to have the expertise in Northern Ireland, based primarily at the Clark clinic. It is part of the enhancement of our cardiological service. The initial key step in all that, irrespective of where the child is ultimately dealt with, will remain here locally. That decision may certainly be for some intervention in Belfast if that is feasible or transfer to Dublin directly if that is the best for that child — or, indeed, transfer elsewhere if that is what is best. It is difficult to generalise or itemise in this scenario. At the end of the day, such decisions are best left to the clinicians. Our role is to ensure that a system is in place to allow them to categorically decide what is best for the child and, as a matter of course, the child is dealt with in that way. That is what we envisage as our role in dealing with such situations.

Mr G Robinson: From a staffing point of view, what role will specialist nurses play in the new service when it is up and running in Dublin?

Dr Woods: A number of roles are laid out in the report, including providing support to families, various clinics and transport facilities; there is a multiplicity of roles. That is in addition to what they largely do already, whether based in Belfast, Dublin or elsewhere.

Mr G Robinson: Where will the extra nurses be based?

Dr Woods: There will still be a significant number based in Belfast because a significant element of the service will remain in Belfast. It is critical to point out that the surgical element is but one element of this service. For most children, that is a one-off episode. The ongoing care of the children will reside with the cardiological and nursing service, which will provide the ongoing support and advice for an increasing part of those children's lifetimes as they get into young and full adulthood. That element of the service will be enhanced. It is not as though everything is disappearing lock, stock and barrel. I would not like anybody on the Committee or beyond to have that impression inadvertently obtained.

Mr G Robinson: How long will it take for those nurses to be put in place?

Dr Woods: The bulk of them are in place as things stand. As part of the detailed proposals and investment plans that we need to work up, I have no doubt that additional nurses or the enhanced skills of current nurses will be an element of that.

The Chairperson (Ms Maeve McLaughlin): I thank all three of you. You have been frank with your comments. We heard the word "assurance" on a number of occasions in relation to the standard of service and the need to have no gaps in the service.

A number of issues were raised in relation to clarification as we move on. One was about the governance and family model and how families, charities and patients have their voices heard in a true and meaningful way and how the Department is proactive in seeking that information. We have also sought clarification on costs. We would appreciate you coming back to us on those issues. We will continue to monitor this vital work and hold you to the assurances that you gave today. Thank you.

Mr Johnston: Happy to do so, Chair.