

Update on the NHS England new congenital heart disease review

Wednesday 9 April 2014

House of Commons, Committee Room 17

Attendee	Position
Chris Ruane	MP Vale of Clwyd and Chair APPG on cardiac disease
Nick Brown	MP Newcastle upon Tyne East
Stuart Andrew	MP Pudsey, Horsforth and Aireborough
Mike Thornton	MP Eastleigh
Mark Durkan	MP Foyle
Steve Brine	MP Winchester & Chandler's Ford
Barry Sheerman	MP Huddersfield
Mohammed Awale	(Young shadow of Barry Sheerman)
Tyson Taylor	Representing Julian Sturdy, MP York Outer
John Cope	Representing Nicky Morgan, MP Loughborough
Meera Sonecha	Representing Sir Edward Gardiner, MP Harborough, Oadby and Wigston
Rob Flaherty	Representing Michael Dugher, MP Barnsley East
Dr Mike Bewick	Deputy Medical Director, NHS England for Sir Bruce Keogh, National Medical Director, NHS England
Michael Wilson	Programme Director, New Congenital Heart Disease Review
Claire McDonald	Engagement Lead, New Congenital Heart Disease Review
Jane Docherty	Project Manager, New Congenital Heart Disease Review

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Chris Ruane MP chaired the meeting introducing the speakers and inviting the room to follow.

Michael Wilson and Dr Mike Bewick presented a summary of the review. They covered structure, methodology, evidence and analysis, proposed standards.

Dr Mike Bewick (MP) spoke first:

The new review was created following Safe and Sustainable and the subsequent judicial review and I'd like to think that we have learnt a lot by that process, and from the issues in our Leeds unit in the last year and recently in Bristol, learning what families and users expect of the services. We are trying to include the evidence from this to give a consistent and standardised approach around the country while recognising the different units have different skill sets and different patient groups.

Population changes mean we need to look at demand and take that into account. We are much better at antenatal and neonatal diagnosis now – in 1980, when I qualified, the severity of heart disease in children meant they were unlikely to reach adolescence. The success story of modern surgery and particularly modern intensive care has transformed outcomes.

We need to get a consistently good service across the country but without threatening any particular unit. To do that we need to concentrate on the form and function of those units, the training and staffing and adopt a professional approach to informatics, particularly data sets that patients and parents can understand. I think the issues around NICOR data etc. have shown the difficulty in non-specialists understanding the data.

We are learning from what we didn't do as well last time and speaking to more groups of people including every provider involved and working with children that have been affected. This is important because many children over the age of 6, particularly those who don't have multi system disease begin to make their own decisions. This means we need to change how we listen to them. At the same time, we look at how this fits in with the whole of the specialised services review and location of services around the country. Organising and coordinating very specialised services that makes sense in terms of accessible patient care whilst adding value to that care is very difficult.

Michael Wilson (MW) – gave a brief update on the work of the review.

Slides of the **presentation** accompany this document.

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Questions:

Chris Ruane MP: What's the perspective with Northern Ireland, Wales and Scotland who will be drawing on your resources?

MW: On the devolved administrations it's quite a complex pattern, which has a different answer for each country. In Wales, most patients would use a surgical service in England, usually coming through the cardiology centre in Cardiff. That means the standards we set, whilst not binding to NHS Wales, certainly affect all of the patients so we would expect to include them in our consultation. There is some cross border flow between Scotland and England. Scotland has its own a surgical centre in Glasgow and own approach to setting standards. Naturally, they will look at ours as they do their own work. We have lines of communication and have invited Clinicians from the Scottish and Welsh units to join our groups, likewise their managers. Northern Ireland has their own process and are trying to decide the future of Congenital Heart Disease services – most recently they have invited a team from the US to give them expert advice. I understand that they are looking to combine services between Belfast and Dublin but we expect some surgical patients would still come to England. Some of their people will be affected by the way we arrange services but probably fewer than in the others.

Chris Ruane MP: I understand that the bigger the throughput, the more experienced clinicians and staff are. Can that be proved – can you say that the busiest of the current 10 centres is the best because it has the biggest throughput? Is good service about getting the experience in those hospitals and centres?

MB: Generally in terms of numbers there certainly is a very good relationship between the numbers of procedures and the overall success of those procedures. Much of that data comes from adult cardiothoracic surgery and Bruce was a great exponent of that. Internationally most of the centres with the lowest mortality rates are larger centres however we are trying to give comparable data because not all centres have the same cases or degree of difficulty. Saying that, the generality of evidence shows that with any potentially life threatening intervention, the more procedures you do the safer it is and the better the long term outcome.

Stuart Andrew MP: This review feels completely different to the last one. I appreciate that openness, transparency and feedback from people is the best approach.

You talked about palliative care and bereavement - how are you going to speak to the hospice movement? Everyone's perception of this traumatic period is different. How are you going to make sure that you are getting the facts rather than the individual's personal experience. Will you be cross checking that with the individual units? In the second stage review at Leeds into some of the experiences of the 16

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families there wasn't a right of reply and so didn't give a clear picture – this was one of our concerns.

MW: Setting the standards was not based on that kind of investigation – some of what we heard probably has a common source with what was reported in Leeds – although they weren't the only people who were telling us those stories. The small group that did the drafting of these standards was a Chief Exec from one of the national charities, a specialist nurse and a psychologist. The first draft has now been reviewed by a wide group of cardiologists with their experience of the service. We have set out what best practice might look like in that area and are consulting everybody, giving them a chance to tell us whether we have got it right, allowing us to take that into account when finalising the standards before we make them part of our service specification.

Stuart Andrew MP: Would you work with some of the children hospices?

MB: You make a good point. All I listen to is people who have bad experiences. The particular aspects of when people complain one has to take seriously and to make sure that the units are answerable. But we do take a wide view because we want to describe what excellent looks like. It's unfair on people who didn't receive good or excellent care and yet if a unit supposedly had policies in place that describe excellent care and it wasn't delivered, that becomes an internal issue for them and staff would need to know. We want to fulfil people's high expectations, especially as this kind of care is relatively planned and they are used to dealing with it.

There are 3 points for all the children and adults:

- Initial diagnosis and getting it right in what we say about what will happen.
- When curative treatment ends and transitions to a palliative pathway the explanation should be well thought out and the environment should be as good as possible.
- End of life stage - arrangement of care

We need to get these areas right for everybody. We've learnt a lot by identifying what went wrong.

Stuart Andrew MP: Do you have any idea when you hope to start commissioning the service?

MW: I can't make a firm commitment because there are still many steps in the process. It is not going to be before June 2015 because we have to give 6 months notice on the contract and this is setting out the standards we expect providers to work to, not an immediate change in the landscape of providers. We know that not everybody can meet all of the standards and we will say which standards have a longer timetable and what that timetable is for example if more staff are required.

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Whatever the date turns out to be, it is not a big bang date, it is a date from which we start to have the expectation that those are the standards and have the expectation that everyone is benchmarking against them and moving towards them.

Stuart Andrew MP: For all existing units then?

MW: It will apply to any unit that is doing this. We are often focussed on children's units but one place where this may make most difference is the larger group of hospitals that provide a bit of care in the adult service. Adult patients tell us they don't want units doing a little bit of congenital surgery so if you are a hospital that is not set up to provide a specialist congenital service, when the standards are published and applied, you are not going to be able to meet them. Then we as a commissioner will not continue to pay you to provide those services. That is probably where you will see the first change not in the specialist units, which will be closer to the standards and will be working towards achieving them.

Steve Brine MP: Are you still clear that you are not starting from the assumption that you have to reduce the number of centres?

MW: We are not making any assumptions about anything. We want to take a stepwise approach. The standards could affect the number of centres – for example they describe how many surgeons should be in a surgical team, how much work each surgeon should do as a minimum.

Steve Brine MP: The reason all this started was that there was a view that it wasn't safe or sustainable to carry on doing congenital heart surgery for children in this many centres and there was a necessity to centralise to a fewer number of centres. Presumably that basis of this ever starting in the first place has not gone away?

MW: We take a slightly different view. We have some different data now than was available then. NICOR data (risk adjusted) doesn't suggest that the units that are doing lower levels of work are unsafe and that is reassuring. They are all in the safe zone, but safe is our minimum standard. We want higher standards of quality across a wide range of measures. What we have got is data about 30 day mortality. We wish that we had a wider set of validated measures. What people tell me is that 30 day mortality is very much a basic measure of the quality of a service. What matters is the quality of life of people that are surviving.

We are clear that there will be a set of standards that we want every unit providing the service to meet. Only when we agree what the standards, are after consultation, and when we have the data on what capacity the service needs on a regionalised perspective (it is important to understand that the capacity has got to be in the right place so we have got to understand what the demand is across the country in a more regionalised view) it is only then that we will be able to take a view of what is the right number and way of arranging those services and when we do that we

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expect there to be a managed process towards making any change happen. We are not anywhere near that view yet.

Chris Ruane MP: You said the number of interventions or operations are growing five times faster than the growth in population – 3% population growth and 15% increase – will that not sort itself out – if you close hospitals will you not reopen them in 15 years time?

MW: One of the reasons we want to do this very carefully, understanding the expected growth, is specifically to make sure that we don't do that. In our thinking we are taking a 10 year view: beyond that is crystal ball gazing. We want to have a sensible view about what is required for the next 10 years and not take action now that would be wrong for the future.

MB: Just to reiterate all the units are safe. The important thing is to move on from 30 day mortality and to move on to describing the standards of quality of life that you would wish for children in this position and that is a very difficult thing to compare. I think we will move to something of a more regional/networked approach. It has to fit in to some extent with the strategic review of other services that deliver acute care for children who are very ill. We will be looking at the number of units and the services they deliver. If it is safe to do that on the current number we will say that. If we had doubts about a unit we would have to come and explain why it would have to close.

Barry Shearman MP:

- The first review created a competition which was unhealthy.
- All my constituents want is the best quality service possible. I find this refreshing, a totally different tone to what we went through before. Consultation over the summer is really 2 months as most people are away so you might want to re-think that.
- What is the supply chain of the Doctors coming through for this specialty? Are we training enough to the highest level?

MB: This is one of the most competitive areas to get a job. We have no shortage of people wanting to be cardiothoracic surgeons. We may need to look at the number we recruit as it is not a stable situation. For paediatric cardiology again that would be one of the areas that people want to do. The specialist nurses are where we may have more difficulty attracting people. On the whole this is an attractive area to work in and I am confident we can recruit the people to do these interventions.

Nick Brown MP: This is some way from where this exercise started in 2001 – the underpinning philosophy is that there would be a smaller number of providers enhancing the outcomes and that we needed to move quickly. 14 years on and you

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are saying to us that because of the number of interventions and the re-assessment of patient profile it won't be necessary to do that?

MW: We recognise that there is a relationship between bigger units and better outcomes but none of the units in this country are small by international standards so we don't think that size alone is the issue.

Nick Brown MP: My understanding was that it was the build-up of expertise

MW: Yes, but it is important to note that over the 10 or 15 years that we have been working at this things have got a lot better in the service - all of the services are good but we want to make sure the services are consistently excellent and fit for the future. We are not starting from the point of knowing that there needs to be a smaller number of units, but it is possible that this is where we will end up. If units can't meet the standards set, then that would still be the conversation, but not because fewer units is our primary end, but because our aim is to make sure that everyone can meet the standards.

Nick Brown MP: It seems at odds with what the clinicians in my Trust are saying: we must centralise but as time goes on things become less safe.

MB: We have 10 paediatric centres so they are already centralised. For adults many more units provide the services. It may be that we have to reduce centres or ask them to work closely as one. The total number may not stay the same. But with a standards based approach, if they can all meet the standards then all of them would be delivering care safely.

Mike Thornton MP: As the surgery gets better it's quite likely, based on past experience, that there will be more operations to be done and if 11 might have been too many two or three years ago, it might not be in three or four as more children survive birth, surgery and pre-natal surgery. So may we need more in 10 years time?

MB: I think it is unlikely we will need more.

Mark Durkan MP: Will what happens in England impact Northern Ireland?

MW: We are having contact with colleagues in Northern Ireland and we have invited them to take part in the groups we are running. We know that at the moment, some of the patients come to England and receive our services and they would be affected by the standards we set. Northern Ireland will take its own view on what service specification it will use. As you are aware there is a piece of work going on looking at the potential for joint working between Dublin and Belfast. I have spoken to the people undertaking that review and we told each other about the work we are doing, so we can make sure we know what is going on across the whole system.

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Mohammed Awale (Barry Sheerman's shadow): What exactly are the terms that you want centres to follow?

MW: That's a really good question because the set of standards that we have produced are vast. It's really hard for us to think how to communicate them easily so we are working with people who use the services to understand how best to do this – how to convey what the standards mean in real terms. It will mean different things to different people. So, some of our standards are about the internal workings of the service and the hospital, and won't be of great interest to people who use the service although they will want to know that they are well set up. Some of the things like how many staff there are in a hospital providing this service will matter a lot, for example people tell us that the specialist nurses are really important to them in explaining what is going on and helping them to understand what is going to happen to them. Our standards say how many there are to be in a hospital, so that there are enough to talk to every patient. There are standards for what equipment they are to have in the hospital as well as what staff. We are trying to describe the other services that these patients will need, not just the ones that are to do with their heart because quite often they will have other problems too. We are also trying to set out how people should talk to patients, the information they need to be given so that they know what is going on and can make choices and know what to expect. It's a really wide range of standards and I think it will be tough for hospitals to meet all of them but it is important as everybody wants the best service.

Meera Sonecha (representing Sir Edward Gardiner): One of the original proposals was to move Glenfield to Birmingham which is a much bigger centre already. But Glenfield specialise in ECMO (extra corporeal membrane oxygenation), they operate on babies a couple of days old and patients are flown in from other parts of the UK because the centre provides ECMO. The concern for the Leicestershire MPs is that the Birmingham centre won't be able to replicate the service. In what sense are you considering the ECMO?

Chris Ruane MP: Has each of the 10 hospitals got a speciality like the ECMO in Leicestershire?

MW: There are three things related to our review that are considered to be highly specialised and commissioned on a national basis which are: complex tracheal surgery, heart transplant and ECMO. All of the centres do some ECMO particularly where it is to do with the heart. Leicester particularly specialises in respiratory ECMO where the problem is mostly to do with breathing. We didn't anticipate working on ECMO when we started doing this piece of work but after consulting with people about the scope of the work, we have decided to set up a group to look at standards for ECMO. We understand the important of ECMO and will have to take it into

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account. The IRP said that we must sort out what the service for congenital heart looks like first and then think about the impact on ECMO services.

MB: One thing we must look at is the overall resilience of the system and Leicester does have a particular interest not only in this area, but also for children with respiratory illness so we have got to think about what the effects would be.