

## **New congenital heart disease review**

On the 9 October 2013, the British Heart Foundation kindly arranged for a meeting of the All Party Parliamentary Group on Heart Disease to be briefed on the new congenital heart disease review by Professor Sir Bruce Keogh, National Medical Director, NHS England and Michael Wilson, Programme Director, the new Congenital Heart Disease review, NHS England.

At the meeting Sir Bruce and Michael talked through the process for the new Congenital Heart Disease Review and how proposals will be developed that aim to 'future proof' services for decades to come.

Key elements of the review were presented - they were:

- this review will look at the whole life pathway - both children's and adult's services
- no decisions had been made about the form or function of the services
- the scope of the review is currently being determined
- the review aims to have developed an implementable solution by June 2014
- the review is not simply looking at mortality but at quality of life and outcomes
- that there are measures in place that will act as early warnings to protect current services during the life of the review
- the review will be open and inclusive
- that NHS England will be working with the devolved administrations to establish how they will work together
- that the review will also take into consideration how related services that are shared by other specialities will be included in the review process
- that a number of groups have been set up to advise the review - further detail of the structure of the review can be found in the accompanying pdf document
- that the decisions that are made will be made in public and will be transparent

Following the presentation there were a number of questions asked by MPs and Lords. They are set out on page 2. Sir Bruce Keogh has provided answers for these questions in an accompanying letter dated 11 November 2013.

Should any further detail be required or you wish to contribute to the review process please contact:

Claire McDonald - [clairemcdonald1@nhs.net](mailto:clairemcdonald1@nhs.net)  
Michael Wilson - [michaelwilson1@nhs.net](mailto:michaelwilson1@nhs.net)

## **Questions from the MPs and Lords**

### **Baroness Masham of Ilton**

Standards are very important, can you tell me who is going to measure the standards?

Is it possible for the surgeons who undertake the very difficult cases to go to where the children and babies are rather than them being moved to the unit?

### **Caroline Nokes MP Romsey and Southampton North**

Has the Southampton model - creating a network that included the John Radcliffe - been thought of as a solution here?

### **Greg Mulholland MP Leeds North West**

We need clarity about the scope of the review and in particular the items that fall outside of the scope already decided by the IRP.

Additionally clarity is required on the process of selection/ inclusion of people forming the boards/panels?

### **Lord Warner**

The relationship between the clinical measurement and the standards that you are going to set is absolutely critical. Can you tell us more about how the set of standards - and the measures that will indicate that they have been achieved - will be established so that the capacity of a centre to meet those standards can be clear from the outset?

### **Paul Goggins MP Wythenshawe & Sale East**

Could you tell us more about the staging posts between now and the end of the review period?

### **Catherine McKinnel MP Newcastle North**

It is clear that the emotive issue of family, family support, the ability provide this support and the geographical location of units is important. We need to know how this is to be taken into account, how this becomes part of the measurement consideration, and if it is to be taken into account. How can it be agreed beforehand so that it doesn't become a big argument afterwards?

### **Lord Woolmer of Leeds**

Has the scope and terms of reference been decided? You have given the impression that it had but I thought that it was still a matter up for discussion.

### **Gisela Stuart MP Birmingham Edgbaston**

Concern has been expressed by Little Heart Matters in Birmingham, that as the time is taken for the review to be undertaken, the infrastructure which is in currently in place will not be sufficiently robust. They want reassurance from NHS England that between now and making the decision, that the infrastructure will be robustly supported?

### **Stuart Andrew MP Pudsey**

Can we have clarity on the decision making process - after the last process felt less than open and public.

## APPG on Heart Disease Attendance List 09.10.13

| Name                   | Organisation/Constituency                                  |
|------------------------|--|
| Baroness Afshar        | House of Lords   |
| Baroness Masham        | House of Lords   |
| Lord Norman            | House of Lords   |
| Lord Warner            | House of Lords   |
| Lord Woolmer           | House of Lords   |
| Alec Shelbrooke MP     | MP – Elmet and Rothwell                                    |
| Caroline Nokes MP      | MP - Romsey and Southampton North                          |
| Catherine Mckinnell MP | MP - Newcastle North                                       |
| Chris Ruane MP         | MP – Vale of Clwyd   |
| Fabian Hamilton MP     | MP - Leeds NE  |
| Gisela Stuart MP       | MP - Birmingham Edgbaston                                  |
| Greg Muholland MP      | MP - Leeds NW  |
| Hillary Benn MP        | MP - Leeds central   |
| John Glen MP           | MP - Salisbury   |
| Nicky Morgan MP        | MP - Loughborough  |
| Paul Goggins MP        | MP - Wythenshawe & Sale East                               |
| Steve Brine MP         | MP - Winchester  |
| Stuart Andrew MP       | MP - Pudsey  |
|                        |  |
| Alistair Longman       | Parliamentary Assistant                                    |
| Florence Cheek         | Parliamentary Assistant                                    |
| Jacob Kostrzewski      | Parliamentary Assistant                                    |
| John Cope              | Parliamentary advisor to Nicky Morgan<br>MP - Loughborough |
| Laura Mullaney         | Parliamentary Assistant                                    |
| Lisa Lovering          | Parliamentary advisor to John Glen MP - Salisbury          |
| M. Kendall             | Staff - Fabian Hamilton MP                                 |
| Jon Newton             |  |
| Anne Keatley Clarke    | Children's Heart Federation                                |
| Julie Wooton           | Max Appeal   |
| Louise Hall            | Little Hearts Matter                                       |
| Michael Cumper         | Chairman of Somerville Foundation                          |
| Rohini Simbodyal       | Children's Heart Federation                                |
| Suzie Hutchinson       | Little Hearts Matter                                       |
| Christy Rowley         | NHS England  |
| Claire McDonald        | NHS England  |