

# Questions and Answers

## The decision making process

### Who are the members of the Panel making your decision?

The members of the panel that carried out the assessment are listed below.

Their role was to assess each hospital's ability to meet the standards, based on the evidence submitted by the Trust. They were not responsible for deciding what action to take as a result of that assessment. At this stage, no final decisions have been taken by NHS England. Final decisions will be taken by the NHS England Board after appropriate engagement, up to and including public consultation.

#### Panel Chair

- Will Huxter, Programme SRO, NHS England

#### Patient and Public

- Michael Cumper, Nominated CRG PPE representative
- Suzie Hutchinson, Nominated CRG PPE representative

#### Clinical

- Professor Deirdre Kelly, Chair, Clinician Engagement and Advisory Group
- Dr Jackie Cornish, Women and Children POC Board
- Dr Trevor Richens, Chair, Congenital Heart Services CRG

#### National Commissioning / Programme (NHS England)

- Anthony Prudhoe, Accountable Commissioner
- Ben Parker, CHD Programme Team
- Cathy Edwards, Operational Delivery Director (National), Specialised Commissioning
- Michael Wilson, Programme Director
- Richard McMahon, Quality Surveillance Team
- Teresa Fenech, Director Of Nursing for Specialised Commissioning

#### Regional Commissioning (NHS England)

- Dr Alison Rylands, Regional Clinical Director for Specialised Commissioning (N)
- Catherine O'Connell, Regional Director Specialised Commissioning (Mid and E)
- Hazel Fisher, AD Programme of Care & NW London Locality Lead
- Dr Vaughan Lewis, Regional Clinical Director for Specialised Commissioning, (S)

### **In your assessments why are outcomes not the decisive factor?**

Only a single measure of outcome is currently available – 30 day post-procedure mortality. We heard from parents that they are looking for more than just survival now. They want to know about the quality of life their children can look forward to and the quality of care they will receive. We do not consider it sufficient to rely solely on a retrospective measure of a single outcome to provide assurance of every aspect of the quality and safety of a service. We have therefore set out a comprehensive range of standards to create a service that can deliver the outcomes throughout life that these patients deserve. While it may be possible to achieve good outcomes without meeting all of these standards, centres that meet the standards are the ones where we as commissioners, acting on behalf of patients, have the greatest assurance that good outcomes will be consistently achieved. We are also ensuring that in future a much wider range of outputs and outcomes are measured and we would be happy to supply further information about our work in this area if required.

### **How quickly will these changes happen? I'm worried about whether my booked appointment / surgery will go ahead.**

We want to reassure patients and families that things are not going to change overnight.

Any change to services in the future will be managed carefully, and will be carried out in partnership with current service providers, and with patient groups and advocates. We will keep you informed every step of the way.

### **If the proposals are accepted, does this mean units are going to close?**

Whether or not the proposals are carried out will be subject to the outcome of public consultation, which will begin later this year. If accepted, it would mean those hospitals no longer provide level 1 CHD services – the most specialist services including surgery and most interventional cardiology. However, if it is decided to implement this proposal, this would not necessarily mean the end of congenital heart disease services at the affected hospitals.

NHS England is keen to work with management and clinicians to explore whether it would be possible to continue to provide level 2 medical CHD services – the majority of specialist medical care. That would mean that CHD patients could still receive their ongoing care and more minor interventions at those hospitals. Patients would then need to travel elsewhere only for the most specialist care, including surgery

### **Why is there a requirement for children's cardiac services to be provided in a place where other specialist children's services are also provided?**

The standards were set following a country wide comprehensive consultation and they follow the advice we received from doctors, nurses, patients and their families. The standards require other children's services to be in the same place as congenital heart services because they are the services that doctors told us are most likely to be needed by the bedside when a child is critically ill, as many children with CHD will have conditions that affect systems and organs other than the heart. This is especially important for the sickest children. The close working relationship between different specialties that develops when they work side by side on a daily basis is particularly important.

### **Why is it so important that a surgeon does 125 operations?**

The standards were set following a country wide comprehensive consultation and they follow the advice we received from doctors, nurses, patients and their families. The standards require consultant surgeon to undertake at least 125 operations a year because congenital heart disease surgeons told us that this was the most important standard in terms of assuring excellent outcomes, and that the number of 125 is a minimum, not an aspiration. We know this is realistic because the evidence supplied by hospitals during the self-assessment exercise shows that some surgeons are already doing many more than 125 operations, which, after all, only equates to three operations per week. 125 surgeries means that surgeons maintain their skills across a range of procedures, which is particularly important in a specialty with a large number of different procedures, and when surgeons are on call.

Commonly asked questions and answers about the implementation of the CHD Standards are set out below – this page will be updated as the programme develops and to reflect additional questions raised by the public and stakeholders.

### **What is the aim of all this? Outcomes are good so why are you making changes?**

Congenital heart disease services in England are very good – they have surgical outcomes comparable with best in the world. Hospitals where we intend to transfer services from have not failed. They and the staff within them deserve great credit for their work – they are rightly proud of their hospitals, and we understand that change is not always easy.

This is about ensuring high quality, consistency and sustainability for the future through common standards. These standards were agreed by clinicians, other

experts and patient and public voice representatives as being the best way to make sure every patient can benefit from the same excellent care.

### **What is the over-riding concern?**

There has been a history of reviews into congenital heart disease services, each making recommendations; but without a national programme of systematic implementation, this has created uncertainty within the speciality, which has damaged relationships between centres, harmed recruitment and retention, and reduced the resilience of services.

It is important now that by implementing the standards we bring that uncertainty to an end and give the service the stability it needs to be able to provide excellent services to patients with CHD and the resilience to be able to plan for the future.

### **Have you spoken to patient groups and parents about what is going to happen now?**

All our patient and public stakeholders have been informed about the proposals we have announced. We have an on-going programme of communication and engagement with patient groups, working with over 30 organisations on a regular basis. They have been involved over the past 2 years creating the standards and ensuring the patients they represent have had opportunity to contribute to the standards creation and the consultation on standards. We will continue to work with patients, their families and patient organisations, and where change is proposed, we will make sure that patients have an opportunity to have their say on them.

### **Do you actually think that services are unsafe now, but you don't want to panic people?**

We know from the data that we receive that services are safe, but we do believe that care can be improved, which is why the standards and their implementation is important. Any changes proposed to a service will be made safely and any changeover is carefully managed with patients.

### **Are the numbers of people with CHD going up?**

Our estimates show that the number of CHD patients using services is going up and this is due to a number of reasons:

- The population is increasing and therefore the number with CHD is increasing
- The number of people living longer with CHD is increasing

Our ability to treat people with CHD is improving and therefore the number of procedures we are doing is rising.

**Are we just talking about children's CHD services or adults as well?**

The new CHD standards apply to the entire lifetime of patients with CHD, encompassing maternity and antenatal care, neonatal, childhood, transition between children's and adult services, adult services and end of life care.

**Are the standards the same as the ones used in the Safe and Sustainable review?**

Some of the standards that were developed for safe and sustainable were agreed to be very good, so they were kept and built upon. We heard from clinicians and patients and families that there were areas that needed to be covered that hadn't been. So we developed standards that covered adult care and areas such as communication, end of life care and dental.

**What makes you think that the approach you are adopting this time around will work? Isn't it the same as Safe and Sustainable?**

We heard from stakeholders that rather than looking at units and locations we should start with standards. A great deal of work has gone into achieving consensus across the board – clinicians, patients and families, providers and other stakeholders – on the standards that providers should meet to ensure that services are high quality and consistent, now and into the future. This process is now about applying those standards to our decision as commissioners of specialised care, based on Trusts' own assessments of whether or not they do and can meet them.

We are clear that these decisions remain subject to the outcome of service change processes in relation to each of the proposed changes. This will include further local public engagement – in each case the process will be appropriate for the scale of the change proposed, up to and including full public consultation.

**What is the timetable for this?**

We will aim to have improvement plans agreed with Trusts very quickly, and where substantial changes to services are proposed, run a full public consultation so that people can have their say. We currently expect that this will start in the autumn, allowing us to make a final decision in late spring / early summer of next year.

**Are there any cost implications to this?**

All the standards have been developed to be able to be delivered within the current tariff.

### **What is the difference between level 1 and level 2?**

The standards are based on a three tier model of care with clear roles and responsibilities (and standards) for each tier. Networks will help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible. The three tiers are:

**Specialist Surgical Centres (level 1):** These centres will provide the most highly specialised diagnostics and care including all surgery and most interventional cardiology.

**Specialist Cardiology Centres (level 2):** These centres provide specialist medical care, but not surgery or interventional cardiology (except for one specific minor procedure at selected centres). Networks will only include level 2 centres where they offer improved local access and additional needed capacity.

**Local Cardiology Centres (level 3):** Accredited services in local hospitals run by general paediatricians / cardiologists with a special interest in congenital heart disease. They provide initial diagnosis and ongoing monitoring and care, including joint outpatient clinics with specialists from the Specialist Surgical Centre, allowing more care to be given locally.

### **Will these changes affect care for heart attacks and strokes at these hospitals?**

Our proposals for change are for children's cardiac and adult congenital heart services only.