*New Congenital Heart Disease Review*

# Patient and Public Group Meeting, 12 November 2013

## Introduction

The patient and public group of the new congenital heart disease review met for the first time on 12 November 2013. The group comprises two nominated representatives from each relevant national and local charity or support group.

A list of those attending the meeting is enclosed as table at the end of this report.

The group is chaired by Professor Peter Weissberg, Medical Director at the British Heart Foundation and the meeting was facilitated by Olivia Butterworth, Head of Patient Voice for NHS England.

The proposed remit of the group is to advise on all aspects of the review that affect service users, helping to ensure that the review results in great patient experience (including the way information is provided to patients and their families, considerations of access and support for families, including when they have to be away from home). The group will also advise on the review's approach to patient and public engagement and provide a user perspective on emerging proposals.

## Presentation

John Holden welcomed participants to the meeting and emphasised the importance of their contribution to ongoing thinking. He gave an update on the review but emphasised that the update should not contain surprises/new material. He noted that the aim was to build on work done to date particularly in those areas that were controversial or perhaps not fully worked through in the previous work. He identified the different strands of work:

- alignment of three different sets of standards dealing with any ambiguity and ensuring that they reflect the model of optimum care;
- analysis using latest data focusing in the first instance on specialist inpatient care and later on other aspects of the service and other interdependent services;
- using the analysis to enable modelling of functions and form to meet capacity requirements;
- commissioning and change model – looking at how NHS England will commission for change ensuring that service specifications translate into practical improvements for patients;
- making sure information is provided that is understandable to all and is timely; and
- early diagnosis that will lead to better and less variable ante-natal detection rates.

John emphasised that the new review team are committed to making the process as open as possible. He also noted that the current timescale for this work is heroic given a number of factors including local government elections, and that the team will let people know if there are changes to this timetable.

The Chair introduced draft Terms of Reference which he explained were deliberately concise and concentrated. The Chair also explained that there would be a robust conflicts of interest declaration for this and other engagement groups.

## Key points

The group felt that it was important to recognise that there is some scepticism given the history of previous reviews in this area, and much expertise to harness outside the new review team. However, there was a full, frank and lively discussion and the group identified a number of areas for further consideration and action.

NHS England must:

- ensure that it continues to pay attention to current service provision throughout the duration of this review;
- ensure that it understands what users expect of services;
- ensure a world class service that is safe and future proof and puts the child first;
- manage the risk of occasional practice – especially (but not only) in the care of adults;
- consider the potential for 'sub-specialisation' – whether every centre should undertake every procedure;
- recognise that sub-specialisation could lead to a two tier service;
- have a level and consistent service across the country – what exactly would it mean to have a national congenital heart service operating to national standards?;
- ensure that there is early detection and diagnosis – and consider how to improve antenatal and neonatal detection rates;
- identify the minimum requirements for training sonographers;
- ensure that information and support are provided at diagnosis;
- establish a national register to support fetal anomaly detection;
- develop clear consistent pathways;
- ensure everyone understands the whole care pathway – it is not just surgery;
- create national standards that are rigorous but have local flexibility;
- be clear, when setting standards, about the minimum number of cases for surgeons or interventional cardiologists, about case mix (of complexity and adults/children) and what number of clinicians is required in a centre to ensure safe cover and a resilient service;
- ensure standards have a maximum or set reasonable distance of travel from home to service;
- beware the perversity of any proposals which would require patients to travel past a congenital centre to be treated elsewhere – i.e. not for good clinical reasons, but simply to 'make up the numbers';
- be clear about activity levels now and in the future;
- widen the sources of data so not just focusing on surgery – and getting good, solid data on types of congenital anomalies;
- consider what outcome measures are needed – experience etc;

- consider who should monitor whether units are meeting standards and how this information is made public;
- move data beyond mortality to include morbidity;
- ensure data is understandable;
- look at what the impact of a growing population will be and how do we identify demand for these services and meet it?;
- ensure effective transitions from children's to adult services and include adult congenital heart services;
- consider co-location for adult and children's services and the essentials of co-location versus what is just desirable;
- ensure that there are adequate adult services as more children survive;
- remove the culture of blame and denial for adverse incidents – when things go wrong families need support, staff need to be able to express grief and/or remorse, and lessons must be learnt;
- ensure there is a system that can respond immediately and effectively when a child has an adverse outcome, to help the family go home or whatever they want to do – most families do not want financial compensation, but understanding, clear explanations, and acknowledgment that what has happened will be reflected upon to try to stop the same thing happening again;
- ensure that hospitals are prepared to refer when they can no longer serve a child/patient – looking for timely referral/ openness if cannot do things/ making it easy to request being transferred elsewhere;
- think about transport and travel for treatment and how practical items like accommodation can be better arranged ;
- consider what is a reasonable and safe distance for travel?;
- recognise there are costs for parents with travel, hotel and maintenance costs when care is being provided at a distance from home;
- have good communication channels that coordinate when receiving care from more than one hospital;
- build and strengthen relationships, in particular between clinicians;
- build an understanding about local and national perspective of delivery of care;
- create a pathway of care that begins prenatally with screening;
- think about the interdependencies of services – and ensure accessibility - need to have joined up services that may be lifelong and address co-morbidities;
- identify important aspects of joined up care and how it is facilitated;
- think about how we can include GPs within the care pathway;
- effective discharge and after care;
- understand expectations of ongoing care;
- need to ensure that network services are of high quality and need to know that more local services are good enough – not just the surgical centres;
- consider international examples especially in relation to clinical networks;
- look at what is happening in the rest of the UK and Ireland;
- monitoring of standards needs to be rigorous, robust, independent and transparent – it should start now with a register of children with CHD so that we can follow and assess the impact of the review;
- consider what has happened to the Kennedy standards;
- identify where funding is going to come from;
- ensure adequate training of workforce;

- improve communication about the aims of the new review to win the confidence of service users;
- need to clarify what the ACHD service is and what is being proposed; and
- ensure that everyone is informed if timelines change.

**Terms of Reference (and communications and engagement issues)**

The Chair introduced draft Terms of Reference which were deliberately concise and concentrated.

Participants asked NHS England to consider the timings of the Patient and Public Group meetings as some participants are volunteers (e.g. have taken a days leave to participate). Consideration should be given to holding some meetings outside of work time e.g. weekends.

Expenses were an issue. NHS England should provide expenses and make clear its policy and processes.

Responding to the governance chart, the group wanted to be clear that there would be two way communication: their voice would be heard and the programme board and Clinical Advisory Panel would respond.

While the blog was helpful, members asked for an email alert that a new blog (or other information) had been published).

The group advised that user engagement needed to go beyond the group:

- Engage with people in their own places.
- Ask local government to help with accessing hard to reach groups.
- Engage with children and young people directly – and remember when organising these meetings / events to avoid school time.
- Ensure that 12 week consultation is inclusive and sensitive to the needs of Black and Asian Minority Ethnic (BAME) populations – especially the south Asian population where CHD incidence is higher.
- Consider encouraging join up between the different groups during the consultation period – charities and support organisations would welcome a meeting with clinicians.
- Think about how we are providing information about the new review – on the internet and elsewhere – and build on the current communications to engage a wider audience.

**Next steps**

It was agreed that there would be a further meeting in the New Year and that as much notice as possible would be given of date and location, and also broad subject matter to enable attendees to consult and prepare.

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### Attendees at meeting on 12 November 2013

| Name | Organisation |
|---|---|
| **Adam Tansey** | KEEPTHEBEAT |
| **Anne Keatley-Clarke** | Children's Heart Foundation (CHF) |
| **Beverley Pearson** | Children's Heart Support Network (CHSN) |
| **Bob Ward** | Save our Surgery (SOS) |
| **Carol Smith** | Children's Heart Support Network (CHSN) |
| **Caroline Langridge** | Young Hearts |
| **Caroline Mutton** | The Brompton Fountain |
| **Christine Stringfellow** | Downs Heart Group |
| **Claire Hennessey** | Max Appeal ! |
| **Emma Lake** | Cystic Fibrosis Trust |
| **Hazel Greig Midlane** | Heartline Families |
| **Jo Diaper** | Families of Oceanward |
| **Jo Wilson** | Evelina Children's Heart Organisation (ECHO) |
| **John Richardson** | The Somerville Foundation |
| **Jon Arnold** | TinyTickers |
| **Julie Wooton** | Max Appeal ! |
| **Lena Pheby** | South West Childern's Heart Circle |
| **Lois Brown** | Children's Heart Surgery Fund |
| **Louise Hall** | Little Hearts Matter |
| **Matthew Sowemimo (Dr)** | Cystic Fibrosis Trust |
| **Maura Gillespie** | British Heart Foundation |
| **Michael Cumper** | The Somerville Foundation |
| **Penny Green** | Downs Heart Group |
| **Philip Williams** | Ben Williams Trust |
| **Richard French** | Heart Link |
| **Robyn Lotto** | KEEPTHEBEAT |
| **Sam Prior** | Families of Oceanward |
| **Sarah Quinlan** | Children's Heartbeat Trust |
| **Sharon Cheng** | Children's Heart Surgery Fund |
| **Suzie Hutchinson** | Little Hearts Matter |
| **Trudy Nickels** | The Brompton Fountain |
| **Vincent Kehoe** | Young Hearts |