

# Update from the Children's Heart Surgery Fund on the CHD Review for the Yorkshire and Humber JHOSC

---

- Since we last updated the JHOSC (13<sup>th</sup> September), CHSF has been pleased by several assurances given by NHSE on the following issues:
  - **Scope** – CHSF made a submission to the Review team on the proposed scope of the new review, informed by our view on the shortcomings of Safe and Sustainable. Following this, the proposed scope was revised to ensure that the Review would:
    - § consider "the whole lifetime pathway of care", including "foetal and neonatal diagnosis of CHD; specialist obstetric care... transition from children's services to adult services..."
    - § take into account congenital heart disease services in Scotland
    - § allow patients and specialists from neonatal, paediatric and adult ICU services as well as transport and retrieval services to participate
  - **Handling Conflicts of Interest** – The Programme Board for the CHD Review agreed a set of rules regarding conflicts of interest and whilst initially these covered only decision-makers, they have now been extended to members of advisory and engagement groups. Again, this is an improvement on Safe and Sustainable, where conflicts of interest were badly managed. There remains, however, the matter of the Patient Experience members of the CHD Clinical Reference Group (see below).
  - **Timescale** – We were told at the Patients and Public Group meeting on 12<sup>th</sup> November that the new Review would take around 6 months longer than planned and so would finish in "late 2014." Given that all units are safe, we believe it is better that the Review reaches the right decision rather than a quick decision and had expressed concerns to NHSE about the impact the original, tight timescale was having on the quality of engagement with patients and families.
- But despite the concerns which have been raised by CHSF and other charities as well as in Parliament, **there still has not been any public assurance on the Patient Experience representatives in the Congenital Heart Services Clinical Reference Group.** CHSF has had private assurances that certain individuals have been removed from the Group but believes that patients, their families and the public deserve openness and transparency on this matter. CHSF recognises that this is something that is not the responsibility of the CHD Review but of others in NHS England.
- CHSF attended the Patients and Public Group meeting on 12<sup>th</sup> November:
  - Well organised
  - Broad spectrum of opinion
  - Everyone given opportunity to speak
  - Obvious tensions between some organisations palpable but overcome

- Concerns raised by local groups and charities that their trusts were not being kept up to date as well as they could be
- Ahead of the public consultation between February and April 2014, CHSF is seeking **to facilitate engagement in the CHD Review by members and representatives of South Asian communities in Yorkshire**, who makeup around one-quarter of the Leeds Children’s Heart Surgery Unit’s caseload yet whose voice was not heard during Safe and Sustainable.