

POSITION STATEMENT

November 2008

Reorganisation of paediatric cardiac services

Children's Heart Federation (CHF) welcomes the review of specialised paediatric cardiac services led by the National Specialised Commissioning Group (NSCG) which aims to take account of the recommendations contained in the Kennedy Report, six years after they were made, and is pleased that it will take account of the interdependencies of specialised services for many children with complex health conditions.

CHF believes that it is necessary to review the current configuration of paediatric cardiac services in order to establish and maintain centres of surgical excellence and CHF recognises that this will result in fewer centres than exist at present. It is essential that:

- paediatric intensive care units have sufficient capacity for the increased number of patients;
- there is sufficient clinical volume at the specialist surgical centres for the development of new paediatric cardiovascular technologies & treatment and training to ensure safe and sustainable practice;
- a formal and robust care pathway is created which allows patients to undergo intensive treatment and surgery at the tertiary centre but receive their outpatient treatment and ongoing care at a centre closer to their homes from fully trained staff (including paediatricians with cardiac training, cardiac liaison nurses, and prenatal radiographers and pharmacologists specialising in cardiac defects) formally linked to the tertiary centre;
- there are co-located fetal and maternity facilities with sufficient funding to support the mother/ neonate dependency; and
- in line with heart transplants, services for complex and rare paediatric cardiac procedures are commissioned nationally from dedicated centres.

CHF is also aware that due to improved life expectancy, the number of adults with congenital heart disease is increasing. As a result, CHF believes that transition between paediatric and adult services must be planned to meet the needs of individual patients. In addition, adult congenital heart services should take account of demand and critical mass and follow the centre structure defined in the NHS GUCH Guide (2006).

Ends

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Notes to editor

- Congenital heart conditions are the most common birth defect in the UK, and a leading cause of birth-defect related deaths world-wide.
- One in every 133 babies in the UK is born with a heart condition (approximately 5000 children each year, with a further 1000 developing a serious heart problem after birth).
- The Kennedy Report (2001) was published following the Bristol Inquiry into the tragic failures of children's heart surgery at Bristol. It set out recommendations to help secure high-quality care for both paediatric cardiac services as well as across the NHS. For more information visit www.bristol-inquiry.org.uk
- The NHS GUCH Guide (2006) is the first guide to outline the structure that the NHS should be providing for adult congenital heart services - http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4134696.pdf
- The Children's Heart Federation is an umbrella organisation with 22 member organisations dedicated to helping children with congenital or acquired heart disease and their families in the UK and Ireland.
- CHF provides information and support through its freephone helpline open Monday to Friday on 0808 808 5000 and its website www.chfed.org.uk