

## **Scope and Interdependencies**

### **Introduction**

1. The new Congenital Heart Disease review has been established to consider the whole lifetime pathway of care for people with congenital heart disease. In order to conduct the review and to ensure that there is a manageable programme of work it is necessary to define its scope in more detail.
2. This paper outlines what is already known about the scope of the review as well as illustrating those areas where more work is needed before a judgement can be made. It also sets out the process by which scope will be defined.

### **Defining scope**

3. Stakeholders have already expressed views on a number of issues and made suggestions about their relationship to the review. Further views will be sought from the Clinical Reference Group and more widely through John Holden's blog and in response to publication of this task and finish group paper. The review's clinical advisory panel will then be asked to advise on the clinical issues at its first meeting on 15 October 2013.
4. It will also be necessary to consider the relationship of the review to the devolved administrations and the potential impact on services for congenital heart disease offered in those countries and used by their populations. This may be different for each country. The NHS in each of the devolved administrations will therefore be asked to agree their relationship to the review and appropriate channels of communication.
5. The final definition of scope will be taken by a subsequent meeting of the task and finish group taking account of the recommendations of the clinical advisory panel and the agreements with the devolved administrations.

### **In scope**

6. As a review of the whole lifetime pathway of care for people with congenital heart disease it is considered that the following will be in scope:
  - a) Improving the quality of care of people with suspected or diagnosed congenital heart disease along the whole patient pathway:
    - Fetal diagnosis of congenital heart disease.
    - Pre-natal care (including care of women whose unborn child has suspected or confirmed congenital heart disease).
    - Care for children and young people.

- Transition from children's services to adult services.
  - Care for adults.
  - End of life care
- b) Care and support for families suffering bereavement and / or poor outcomes from surgery or other intervention for congenital heart disease.
- c) The review covers all care for congenital heart disease commissioned by the NHS for people living in England.

### **Out of scope**

7. The following services related to or used by congenital heart disease services are considered to be out of scope, but links with these services will need to be managed by the review (the way in which these relationships will be managed will be set out in the programme initiation document):
- Neonatal, paediatric and adult intensive care unit (ICU) services and transport and retrieval services.
  - Other interdependent clinical services (for example other tertiary paediatric services).
  - Local maternity services.

### **To be determined**

8. There are a number of other related clinical services where a judgement will need to be made about whether they should be in scope for the review.
- Children, young people and adults with congenital heart arrhythmias.
  - Children and young people with acquired heart disease.
  - Children and young people with inherited heart disease.
  - Adults with inherited heart disease.
  - Cardiac extra corporeal membrane oxygenation (ECMO) for children and young people.
  - Respiratory ECMO for children and young people.
  - Cardiac extracorporeal life support (ECLS) for adults.
  - Respiratory ECMO for adults.
  - Complex tracheal surgery.
  - Heart transplant and bridge to transplant services for child and young person.
  - Heart transplant for adults.