

Scope and Interdependencies

Introduction

1. The new Congenital Heart Disease (CHD) 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. Patients, clinicians and the public have been asked to advise on what services and conditions should be included in the scope of the new review. Approximately 40 responses were received (these will be made available to the Task and Finish Group in hard copy for reference).
3. NHS England originally proposed three categories (in scope; out of scope; to be determined). It was apparent from the responses received that not enough explanation had been given to respondents which had led to some misunderstanding of the concept of scope. It was also apparent that the reality is more complicated than a simple 'in' or 'out'. There are multiple, complex interdependencies, so this paper recommends a less binary, more nuanced approach that explains how the review relates to a range of other services and conditions, rather than simply declaring them to be either 'in' or 'out' of scope. At the same time, it is important to define the boundaries in such a way that there is a realistic prospect of completing the review and avoids mission creep.
4. A paper was written for the Clinical Advisory Panel summarising stakeholder responses. Members were also provided with the full original responses for reference. The panel met on 15 October 2013 and considered the scope of the review. This paper reflects that group's recommendations.
5. 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. Cross-border flows are significant and need to be taken into account. The NHS in each of the devolved administrations will therefore be asked to agree their relationship to the review and appropriate channels of communication.

Summary recommendations

6. In summary the panel recommends that:
 - A. The heart of the review should be the whole lifetime pathway of care for people with congenital heart disease, and specifically congenital heart disease services.
 - B. There are a number of clinical conditions which while not CHD receive their care wholly or mainly from congenital heart services. The standards for services for these conditions should not be reviewed as part of the review (though the standards being developed may address aspects of the service). However, patients

who fall within this category use congenital heart services and should be able to participate in the review.

- C.** There are a number of services beyond congenital heart services that CHD patients may use. Some of these services are reliant on clinical support or backup from CHD specialists. The standards for these services should not be reviewed as part of the review. However, the use of these services by congenital heart disease patients should be considered by the review, including the definition of clinical pathways and referral routes. Any impact of changes recommended by the review on these services should be considered prior to decisions being taken and during implementation. Patients and specialists from these services should be able to participate in the review.

Detailed recommendations

7. Based on these principles, the Clinical Advisory Panel recommends that:

In scope

8. The heart of the review should be the whole lifetime pathway of care for people with congenital heart disease, and specifically congenital heart disease services. This means:
- a) Improving the quality of care of people with suspected or diagnosed congenital heart disease (including those with congenital heart arrhythmias or arrhythmias in the context of congenital heart disease) along the whole patient pathway:
 - Fetal and neonatal diagnosis of CHD
 - Specialist obstetric care (including both care of women whose unborn child has suspected or confirmed CHD and care of pregnant women with CHD)
 - Care for babies, children and young people
 - Transition from children's services to adult services
 - Care for adults
 - End of life care
 - b) Cardiac and respiratory extracorporeal membrane oxygenation (ECMO) for children and young people.
 - c) Care and support for families suffering bereavement and / or poor outcomes from surgery or other intervention for congenital heart disease.
 - d) The review covers all care for congenital heart disease commissioned by the NHS for people living in England.

Interdependencies

9. There are a number of clinical conditions which while not CHD receive their care wholly or mainly from congenital heart services. The standards for services for these conditions should not be reviewed as part of the review (though the standards being developed may address aspects of the service). However, patients who fall within this category use congenital heart services and should be able to participate in the review. This means:
 - a) Children and young people with acquired heart disease
 - b) Children and young people with inherited heart disease (for which a separate service specification has already been developed).

10. There are a number of services beyond congenital heart services that CHD patients may use. Some of these services are reliant on clinical support or backup from CHD specialists. The standards for these services should not be reviewed as part of the review. However, the use of these services by congenital heart disease patients should be considered by the review, including the definition of clinical pathways and referral routes. Any impact of changes recommended by the review on these services should be considered prior to decisions being taken and during implementation. Patients and specialists from these services should be able to participate in the review. This means:
 - a) Neonatal, paediatric and adult intensive care unit (ICU) services, and transport and retrieval services.
 - b) Other interdependent clinical services (for example other tertiary paediatric services).
 - c) Mechanical circulatory support for adults including cardiac ECMO and VAD.
 - d) Complex tracheal surgery.
 - e) Heart transplant and bridge to transplant services for children and young people.
 - f) Heart transplant for adults.

Out of scope

11. Adults with inherited heart disease
It was recommended that this group be excluded from the review because these patients do not receive their care from congenital heart services.

12. Adult respiratory ECMO
It was recommended that this service should be excluded from the review because it is not dependent on congenital heart services, and operates independently of ACHD services.

13. Local maternity services
It was recommended that local maternity services should be excluded from the review. Rather, the review should include specialist cardiac obstetric care (see 7a) above).