1. **Title**

Congenital Heart Disease Standards

2. **Healthcare Improvement Scotland standards and indicators**

Healthcare Improvement Scotland (HIS) is the national health and social care improvement organisation for Scotland. It provides the expertise and resources to co-produce health and social care standards which are developed, informed and shaped by those who commission, deliver and use services.

The role of standards is to:

- provide a statement(s) of an expected level of service which demonstrates delivery of person-centred, safe and effective healthcare
- promote understanding, comparison and improvement of care, and
- support national consistency and/or local improvement.

3. **Clinical need**

Congenital heart disease (CHD) is a general term for a range of birth defects that affect the normal way the heart works. The term “congenital” means the condition is present from birth. CHD is one of the most common types of birth defect, affecting up to 8 in every 1,000 babies born in the UK\(^1\).

Improved outcomes for patients with CHD have been achieved through enhanced detection and improvements in paediatric surgery resulting in an increased number of patients reaching adulthood. There is no definitive register of CHD in Scotland but approximations suggest that there are 20,000 people living with this condition and it is anticipated that the number will continue to increase\(^2\).
The National Services Division (NSD)* published specialist adult and paediatric CHD standards in 2018 which cover the CHD national services provided at the Royal Hospital for Children (RHC), Glasgow and at the Golden Jubilee National Hospital (GJNH), Glasgow. Local provision of CHD services varies across NHS Boards and there are currently no standards to support the delivery of local services.

NSD has asked the HIS Standard and Indicators team to develop standards for adult and paediatric CHD that cover local services and will apply to all NHS boards in Scotland. The proposed HIS standards will cover the entire patient journey with specific reference to key stages of the pathway e.g. access to and transition between paediatric and adult services. An aim of this work is to improve quality of care by enabling consistency of CHD service delivery across Scotland.

4. **The scope of the standards**

4.1 **Population that will be covered**
- Children and adults with CHD.

4.2 **Healthcare and/or social care setting**
- All NHS boards responsible for the delivery of local services to people living with CHD in Scotland.

4.3 **Areas for standards development**

a. Areas that will be covered:
- Leadership and governance
- Information, communication and support
- Education and training
- Transition between paediatric and adult services
- Inter-related specialties and support services
- Outpatient/inpatient care
- Pregnancy care and contraception
- Fetal diagnosis
- Emergency care
- Person-centred care
- Palliative care and bereavement

The importance of audit, quality assurance and inequalities will be woven throughout the standards.

*NSD is a division of NHS National Services Scotland (NSS)
b. Areas that will not be covered:

- Individuals with inherited or acquired heart disease
- Development of HIS quality indicators or key performance indicators
- Implementation of the standards - this is for local determination

5. Key publications

- NHS England Congenital Heart Disease Standards 2016
- National Services Division Specialist Congenital Heart Disease Standards for children and adults in Scotland 2018
- Scottish Government Heart Disease Improvement Plan 2014

6. Timelines

The congenital heart disease standards will begin development in November 2019 and are due for completion by September 2020.

7. Proposed development group specialists

The proposed specialists to be represented during the congenital heart disease standards' development process are:

- Cardiac Rehabilitation Nurse
- Cardiac Rehabilitation Physiotherapist
- Consultant Adult Cardiologist (local and national)
- Consultant Paediatric Cardiologist (local and national)
- Consultant Paediatrician with expertise in CHD
- Cardiac Physiologist
- General Practitioner
- HIS Quality Assurance representative
- National Services Division representative
- People with lived experience and parents of those children with CHD
- Psychologist
- Radiographer
- Scottish Government representative
- Specialist CHD nurse (adult and paediatric)
- Third sector representation

Specialist or technical input will be sought from NHSScotland representatives as appropriate. Where a specialist cannot be represented on the development group, there will be opportunities for engagement through consultation or peer review.
8. **Contact us**

For any enquiries please contact:

- Fiona Wardell, Standards and Indicators Team Lead, fionawardell@nhs.net
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For more information about HIS, visit our website:

www.healthcareimprovementscotland.org

**References**


