We are committed to advancing equality, promoting diversity and championing human rights. These standards are intended to enhance improvements in health and social care for everyone, regardless of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socioeconomic status or any other status. Suggested aspects to consider and recommended practice throughout these standards should be interpreted as being inclusive of everyone living in Scotland.

We carried out an equality impact assessment (EQIA) to help us consider if everyone accessing health and social care services will experience the intended benefits of these standards in a fair and equitable way. A copy of the EQIA is available on request.

Healthcare Improvement Scotland is committed to ensuring that our standards are up-to-date, fit for purpose and informed by high quality evidence and best practice. We consistently assess the validity of our standards, working with partners across health and social care, the third sector and those with lived and living experience. We encourage you to contact the standards and indicators team at his.standardsandindicators@nhs.scot to notify us of any updates that might require consideration.
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Introduction

Background to the congenital heart disease standards

Congenital heart disease (CHD) is a general term for a range of conditions that affect the way the heart works. The term ‘congenital’ means the condition is present from birth. CHD affects up to 8 in every 1,000 babies born in the UK.\(^1\) There are approximately 20,000 people in the UK who live with this condition and it is anticipated that the number will continue to increase in the future through advances in detection and paediatric surgery.\(^2\) The number of babies and children with CHD living to adulthood has increased by approximately 75% over the last 60 years. For every person and family affected, there can be a unique range of medical, social and psychological challenges associated with living with a lifelong cardiac condition.

In Scotland, there are national specialist services for both children and adults provided at the Royal Hospital for Children in Glasgow and at the Golden Jubilee National Hospital. These services are commissioned by NHS National Services Division on behalf of the Scottish Government. They are known as the paediatric or adult ‘national service.’

In 2018, NHS National Services Division (NSD) published standards for the national services. Following this, Healthcare Improvement Scotland began developing standards for all NHS boards across Scotland where people receive lifelong care outside the national services.

Policy context

In 2012, a public petition\(^3\) seeking the development of standards for CHD in Scotland led to the development of the Scottish Congenital Cardiac Network (SCCN), a national managed clinical network. The SCCN was decommissioned two years later and its work was subsumed by the Scottish Congenital Cardiac Advisory Board (SCCAB). The role of the SCCAB is currently under review.

In 2021 the Heart Disease Action Plan (Scotland) made explicit reference to improving care for the growing population of people with CHD.\(^2\) The plan highlighted the importance of psychological support, cardiac rehabilitation and palliative care.
Key principles

These standards aim to ensure that:

- people’s rights are upheld
- there is early detection and intervention for people with CHD
- people experience high quality, lifelong care provision.

The standards are underpinned by human rights and seek to provide better outcomes for everyone. The standards promote and uphold the:

- International Covenant on Economic, Social and Cultural Rights.\(^4\)
- United Nations Convention on the Rights of the Child.\(^5\)
- United Nations Convention on the Rights of Disabled People.\(^7\)
- General Comment No. 22 from the UN Committee on Economic, Social and Cultural Rights.\(^8\)

Scope of the standards

The Healthcare Improvement Scotland congenital heart disease standards cover:

- leadership and governance
- person-centred care and shared decision making
- staff education and training
- mental health and emotional wellbeing
- fetal diagnosis
- outpatient care
- shared care
- transition between paediatric and adult services
- preconception and pregnancy care
- emergency care
- palliative care and bereavement.
Format of the standards

All Healthcare Improvement Scotland standards follow the same format. Each standard includes:

- an overarching standard statement
- a rationale explaining why the standard is important
- a list of criteria describing what is needed to meet the standard
- what the standards mean if you are a person with congenital heart disease
- what the standards mean if you are a member of staff
- what the standards mean for organisations
- examples of what meeting the standard looks like in practice.

Implementation

Healthcare Improvement Scotland has published these standards to inform self-evaluation and improvement. Healthcare Improvement Scotland may use these standards in a range of assurance and inspection activities. They may be used to review the quality and registration, where appropriate, of health and social care services.

There are no plans for Healthcare Improvement Scotland to use these standards as part of specific inspections or routine external quality assurance. These standards complement existing Healthcare Improvement Scotland quality assurance programmes.

The Healthcare Improvement Scotland Quality Management System (QMS) Framework supports health and social care organisations to apply a consistent and coordinated approach to the management of the quality of health and care services. More information about this framework is available on the HIS website.
Terminology

Wherever possible, we have incorporated used generic terminology which can be applied across all health and social care settings. The terms ‘people’, ‘person’ or ‘individual’ are used within the criteria to refer to the person receiving care or support.

The term representative refers to any person the individual wishes to be involved in their care.

The term family refers to a person’s spouse or siblings, parents, foster carers, kinship carers and siblings, adoptive families and extended family.

The terms pregnant women and maternal are used in relevant standards to refer to people, including trans and non-binary people, who are pregnant. This terminology is in line with the NICE Quality Standards for intrapartum care for existing medical conditions and obstetric complications and the National Pregnancy Screening Programme for Scotland.9, 10

The national service refers to the specialist paediatric or adult CHD service provided at the Royal Hospital for Children in Glasgow or at the Golden Jubilee National Hospital.

Local congenital cardiac nurse refers to an appropriately qualified nurse with special interest in CHD who works within territorial NHS boards. This role involves providing ongoing support, coordination and advice where required for adults and children with CHD.

Link adult cardiologist refers to an appropriately trained cardiologist who delivers services for adults with CHD within territorial NHS boards. This role involves collaboration with the national service.

Link paediatrician refers to an appropriately trained paediatrician with a special interest in cardiology or congenital cardiology who delivers services for children with CHD in their local NHS board. This role involves collaboration with the national service.
How to participate in the consultation process

We welcome feedback on the draft standards and will review every comment received. We are using different methods of consultation, including:

- online and face-to-face engagement
- meeting and event attendance to raise awareness and hear feedback
- an online survey tool: https://www.smartsurvey.co.uk/s/QMOVEZ/

Submitting your comments

Responses to the draft standards should be submitted using our online survey: https://www.smartsurvey.co.uk/s/QMOVEZ/.

The consultation closes on 6 September 2023. If you would like to submit your comments using a different format, please contact the project team on his.standardsandindicators@nhs.scot.

Consultation feedback

At the end of the consultation period, all comments will be collated and the Standards Development Group will respond to each comment received on the draft standards. The response will explain how the comments were taken into account in producing the final standards.

A summary of the responses to the consultation will be made available on the Healthcare Improvement Scotland website (www.healthcareimprovementscotland.org).

The final standards will be published in November 2023.
Summary of standards

Standard 1: NHS boards demonstrate leadership and effective governance to deliver their local CHD service.

Standard 2: People with CHD can access information that is right for them and are supported to participate in decisions about their care.

Standard 3: Staff have the training and skills to deliver the right care and support for people with CHD.

Standard 4: NHS boards provide a trauma-informed CHD service and ensure people with CHD can access support if they need it.

Standard 5: NHS boards have processes and pathways in place to support early diagnosis and effective management of fetal CHD.

Standard 6: NHS boards provide high quality outpatient care for people with CHD.

Standard 7: NHS boards ensure that people with CHD have access to appropriate specialist services, support and advice.

Standard 8: NHS boards ensure that people with CHD experience seamless and person-centred transition between paediatric and adult services.

Standard 9: Women with CHD who may become pregnant receive preconception care, counselling and specialist pregnancy care.

Standard 10: NHS boards ensure that emergency care for people with CHD is safe and effective.

Standard 11: NHS boards provide high quality and compassionate palliative and bereavement care.
Standard 1: Leadership and governance

Standard statement
NHS boards demonstrate leadership and effective governance to deliver their local CHD service.

Rationale
NHS boards are responsible for the delivery of a high quality, lifelong CHD service for their respective populations. Safe, effective and person-centred services require strong leadership and governance. This includes accountability, adverse events management, escalation procedures and data monitoring.\textsuperscript{11,12} NHS boards must oversee the whole CHD care pathway, from fetal diagnosis to ongoing treatment and care.\textsuperscript{13} This requires the use of data to measure and plan improvement.

Good clinical care and governance requires clear, integrated arrangements. People with CHD and their families or representatives are an integral part of the design and monitoring of services.\textsuperscript{14} Feedback allows NHS boards and services to plan improvements based on what matters to people. A nominated lead clinician for paediatric and adult services provides essential oversight and assurance.

Criteria

1.1 NHS boards demonstrate robust governance arrangements across the CHD service, with clear lines of accountability, covering all aspects of the person’s care pathway.

1.2 Each NHS board can demonstrate:
   - protection of people’s rights
   - implementation of the Health and Social Care Standards.

1.3 NHS boards have nominated lead clinicians who work collaboratively to provide:
   - paediatric CHD care and support
   - adult CHD care and support.

1.4 NHS boards participate annually in a national joint adult and paediatric CHD steering group which is responsible for:
   - reviewing the quality and effectiveness of CHD services
   - implementation of the HIS CHD standards
   - quality improvement activities.
1.5 NHS boards have systems and processes to demonstrate:
   - implementation of relevant policies, procedures, guidance and standards
   - use of meaningful data to monitor performance and drive improvement
   - adherence to safe staffing legislation
   - compliance with professional and organisational codes of practice.

1.6 NHS boards have a local structured escalation and adverse events process, in line with national policy, which includes:
   - who is responsible and accountable for reporting any adverse events
   - a standard and consistent approach to reporting
   - a documented escalation process and incident management process
   - processes for monitoring actions and learning from adverse events.

1.7 NHS boards demonstrate their commitment to addressing health inequalities through:
   - effective aggregated and anonymised data collection on the CHD population
   - meaningful engagement with people with CHD and their families from all backgrounds.

1.8 NHS boards have pathways in place to ensure that people with CHD have access to:
   - a local congenital cardiac nurse
   - psychological support
   - cardiac rehabilitation for adults with CHD.\textsuperscript{15}

1.9 People living with CHD have the option of care close to home or the most accessible service for them.

1.10 NHS boards work nationally, regionally and locally to continuously improve service design and structure through:
   - joint improvement work
   - digital and technological advancement
   - feedback from people with CHD and their families.
### What does the standard mean for people with CHD?

- The CHD service monitors and reviews its performance to keep improving.
- Staff work together to provide you with a high quality service.
- You can be part of the design and monitoring of the CHD service if you want to be.
- There is a system to learn from others and share good practice.

### What does the standard mean for staff?

**Staff:**

- are provided with effective leadership
- are aware of how to report and escalate adverse events
- work according to clear guidelines and standards
- can share feedback to inform service improvements
- are aware of how to report and escalate adverse events.

### What does the standard mean for the organisation?

**The NHS board:**

- provides high quality care and support services to people with CHD
- involves people with CHD in service design and review
- has governance arrangements in place demonstrating roles and responsibilities and lines of accountability, including escalation routes, adverse events management and incident management
- records and monitor data to continuously monitor performance
- undertakes quality improvement and assurance activities.

### Examples of what meeting this standard might look like

- Documentation describing lines of accountability, roles and responsibilities, escalation routes, incident management and adverse events management reporting.
- Documents describing learning and improvement from adverse events.
- Documentation describing representation on a national steering group.
- Multidisciplinary working, including involvement of professionals, care pathways, and local standard operating procedures.
- Action plans demonstrating implementation of the HIS CHD standards.
- Improvement work, data collection and review of data, including feedback from people with CHD.
Standard 2: Person-centred care and shared decision-making

**Standard statement**

People with CHD can access information that is right for them and are supported to participate in decisions about their care.

**Rationale**

People are individuals and experts in their own condition. Person-centred care involves people and services working together in partnership.\(^ {16}\) It is based on each individual’s personal goals, preferences and needs.\(^ {17} \) This results in more effective care with better outcomes for people living with CHD.\(^ {13} \)

Being part of discussions and decisions about their care requires people to be fully informed and taken seriously. People can be empowered when they are supported to make decisions about what matters to them.\(^ {18} \) Information should be available in the format and language that is right for the person. The format should take into account age, psychological, social, cultural and spiritual factors.

**Criteria**

2.1 People with CHD are fully informed, listened to, involved in and supported through all stages of their care.

2.2 People with CHD are supported to develop the knowledge, skills and confidence to manage their own condition and medication, as appropriate.

2.3 Families and representatives of people with CHD are fully informed and involved in discussions and decisions, where appropriate.

2.4 People with CHD have:

- a summary of their medical history and care plan
- further access to their records and relevant information about themselves and their care if requested.

2.5 NHS boards ensure people with CHD can:

- participate in shared decision making at all stages of their care
- raise questions or concerns
- provide feedback on their care and experiences.
2.6 NHS boards provide people with CHD (and their families or representatives, where appropriate) with:

- information and support that is relevant to their language, age, circumstances and diagnosis
- contact details of relevant health professionals
- information about the service, including who to contact and how to arrange appointments.

2.7 People with CHD (and their families or representatives, where appropriate) receive:

- social, financial, educational and occupational advice
- practical support to manage their condition.

2.8 People can choose to access remote or in-person consultations or appointments where appropriate.

2.9 Staff ensure that informed consent is obtained prior to using medical information as a teaching case.

What does the standard mean for people with CHD?

- You are recognised as an individual and treated with compassion and respect.
- You will be involved in discussions and decisions about your care and support.
- You receive information and support on CHD and the care and treatment you will experience or be offered.
- Information is in a format and style that is right for you.
- You can discuss any aspect of services or care, raise questions or concerns and provide feedback.
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<td><strong>Staff:</strong></td>
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<tr>
<td>• support and listen to people with CHD</td>
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<tr>
<td>• actively engage with people to understand their needs and preferences</td>
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<tr>
<td>• understand that people are affected by CHD in different ways and offer appropriate support that reflects individual needs and preferences</td>
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<tr>
<td>• can support people (and their representatives where appropriate) to reach informed decisions in partnership with their healthcare professionals</td>
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<tr>
<td>• signpost people to current information and support appropriate to their needs.</td>
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<th>What does the standard mean for the organisation?</th>
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<td><strong>NHS boards:</strong></td>
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<tr>
<td>• have systems and processes to ensure they deliver responsive care and support</td>
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<tr>
<td>• ensure the availability of appropriate, easily accessible and timely information and support</td>
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<tr>
<td>• have mechanisms to record and act upon feedback from people and their representatives</td>
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<tr>
<td>• ensure that staff have time and resources to support and care for people.</td>
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<tr>
<th>Examples of what meeting this standard might look like</th>
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<tbody>
<tr>
<td>• Evidence of information provided in alternative formats and languages, taking account of the needs of people who may be digitally excluded.</td>
</tr>
<tr>
<td>• Clinical audit of CHD consultations with documentation of signposting or written information being provided.</td>
</tr>
<tr>
<td>• Evidence of patient involvement in decision making, tools for shared decision making, and effective communication.</td>
</tr>
<tr>
<td>• Ongoing engagement with people with CHD and their families or carers.</td>
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<tr>
<td>• Evidence of any changes made based on feedback received.</td>
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<tr>
<td>• Evidence of support for people with additional communication needs, for example, people with sensory impairments or difficulties with speech and language.</td>
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<tr>
<td>• Signposting and supporting people to access other support services.</td>
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<tr>
<td>• Documentation relating to decision-making, feedback questionnaires and other communication methods relating to care plans.</td>
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Standard 3: Staff education and training

Standard statement
Staff have the training and skills to deliver the right care and support for people with CHD.

Rationale
The delivery of care for people with CHD requires specialist knowledge. CHD is a complex condition and people often experience additional health and wellbeing challenges associated with it. Any staff across the health and social care system may provide care to people with CHD. Sensitive and compassionate staff understand and respond appropriately to people who may have experienced trauma.

As people with CHD are a growing population group, specific future workforce planning is required. Services need to raise awareness of CHD in all areas likely to care for this population. This includes providing opportunities for training or placements where possible.

Criteria

3.1 NHS Boards collaborate with stakeholders to ensure that there are adequate training opportunities for people involved in the care of people with CHD, including undergraduate and postgraduate doctors, nursing, midwifery, healthcare scientists and allied health professionals.

NHS boards ensure that access is facilitated and staff are encouraged to take part.

3.2 Staff involved in CHD care across the NHS board:

- undertake training, reflective practice or clinical supervision as appropriate to develop and maintain skills, knowledge and competence
- have their education and training needs aligned to professional development frameworks
- implement a multi-professional approach to improve knowledge, communication and partnership working.

3.3 NHS boards support staff to increase their awareness and knowledge of CHD by providing access to tailored local training for staff working in:

- obstetric cardiology
- allied cardiac services
- emergency departments
- primary care.
3.4 Staff have access to information and training to enable them to support the holistic needs and rights of people living with CHD.

3.5 Staff involved in the delivery of paediatric and adult outpatient CHD care have adequate training on aspects specific to the CHD population including:
   - equalities and rights including communication needs
   - understanding and awareness of people’s needs
   - associated conditions and comorbidities.

3.6 NHS boards have processes and protocols in place to share learning from complaints and adverse events with staff, locally and nationally.

3.7 Each NHS board ensures that people with CHD are supported:
   - by informed staff who have awareness of the person’s condition
   - by compassionate staff who take time to understand and respect their wishes and personal outcomes.

3.8 Staff wellbeing is supported through ongoing personal and peer support.

<table>
<thead>
<tr>
<th>What does the standard mean for people with CHD?</th>
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<tr>
<td>• The team who look after you are be trained, skilled, knowledgeable and competent.</td>
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<td>• You are treated with dignity and compassion.</td>
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<th>What does the standard mean for staff?</th>
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<td>Staff:</td>
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<td>• can demonstrate knowledge, skills and competence relevant to their role and responsibilities</td>
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<tr>
<td>• attend and participate in relevant training</td>
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<tr>
<td>• receive accurate and current information to enable them to support people</td>
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<tr>
<td>• provide opportunities for health professionals in training.</td>
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</tbody>
</table>
### What does the standard mean for the organisation?

The NHS board:

- plans for the needs of the future CHD population
- provides staff with the necessary knowledge and skills, appropriate to their roles and responsibilities, to provide high quality care and support
- provides ongoing support for continued development
- invests in and develops its future CHD workforce.

### Examples of what meeting this standard might look like

- Provision and uptake of multidisciplinary and multi-agency training.
- Partnerships between NHS boards, hospitals or services and higher education institutions.
- Provision of study leave, training placements or specialist training modules.
- Provision and uptake of staff education and training in quality improvement methodology relevant to their role and responsibilities.
- Competency and professional development frameworks.
- Implementation and maintenance of safe staffing levels.
- Use of incident reports or significant event analysis for learning, reflecting and supporting training action plans.
- Training and skills needs and gap analyses.
Standard 4: Mental health and emotional wellbeing

Standard statement
NHS boards provide a trauma-informed CHD service and ensure people with CHD can access support if they need it.

Rationale
Many people with CHD can experience psychological, financial and social challenges. Up to 50% of people with CHD are diagnosed with anxiety, depression or post-traumatic stress disorder in their lifetime. Good relationships, consistency of care and trust between people with CHD and the service is critical. Services should be designed to promote wellbeing and psychological safety. They should promote safety, trustworthiness and transparency, choice, collaboration, mutuality and empowerment and understand the reality of people’s lives and experiences.

Serious illness is an adverse childhood experience. Frequent hospital stays and medical interventions can be traumatic and distressing for children. This can disrupt babies’ early attachment, which is important for the long-term mental health of both children and parents or carers. Disruption to early attachment can affect children’s behaviour and social cognition. Support for the whole family supports children to recover. Parents and carers of children with CHD should be offered support for their mental health.

People with CHD often have neurocognitive difficulties or disabilities which affect executive function, memory, language and communication. People should receive specialist support in a way that is right for them.

Adults with CHD, particularly people who were diagnosed many years ago, may require enhanced support which takes into account their historical experience of care.

Criteria

4.1 NHS boards have established pathways and arrangements with formal and informal specialist support services for people with CHD.

4.2 NHS boards develop plans to meet quality frameworks for trauma-informed care.

4.3 People with CHD, and where appropriate, their families, can access support from a local congenital cardiac nurse, who can provide continuous emotional wellbeing support and advocacy.
4.4 Staff use validated screening tools to identify the support needs of people with CHD and, where appropriate, their families.

4.5 Staff refer people to third sector services, peer support, financial support and educational services as required.

4.6 People with CHD, and where appropriate their families, have access to an initial appointment for their mental health which:

- meets their needs
- upholds their rights
- is as close to home as possible
- is within 12 weeks.\(^{38}\)

4.7 People with CHD are informed about options for continuous or ongoing support for their mental health and emotional wellbeing, including unscheduled mental health support.

4.8 Staff are supported to understand the unique emotional and psychological needs of the person with CHD.

4.9 People with CHD can:

- meet staff members and see places or equipment before appointments, where possible
- choose someone they know to be with them or nearby
- discuss any concerns or anxiety that they may have before appointments or interventions.

4.10 Parents or carers of children with CHD are offered:

- continuous face-to-face connection with babies and children\(^{39}\)
- ongoing and continuous support for their own mental health or emotional wellbeing
- signposting to relevant support organisations
- pre-emptive support at key stages of a child’s life.

4.11 Enhanced and tailored support as required is provided for:

- children and young people
- people with social communication needs, learning disabilities or additional support needs.
4.12 Staff have access to peer support and supervision to:

- prevent, respond to and understand challenging situations
- continue to provide high quality person-centred care.

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<thead>
<tr>
<th>What does the standard mean for people with CHD?</th>
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<tr>
<td>• Your mental health and emotional wellbeing will be considered throughout your treatment.</td>
</tr>
<tr>
<td>• Staff understand the reality of your experience and the impact it may have had on you.</td>
</tr>
<tr>
<td>• Your concerns will be listened to and taken seriously.</td>
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<tr>
<td>• If you need support for your mental health or emotional wellbeing, you know where to go or who to turn to.</td>
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<th>What does the standard mean for staff?</th>
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<tr>
<td>Staff:</td>
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<tr>
<td>• know who to refer to if someone they are looking after needs support for their mental health or emotional wellbeing</td>
</tr>
<tr>
<td>• receive support for their own mental health and emotional wellbeing</td>
</tr>
<tr>
<td>• adhere to the principles of trauma-informed care</td>
</tr>
<tr>
<td>• promote early attachment and bonding between babies and their parents or carers</td>
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<tr>
<td>• recognise and respond to trauma associated with medical intervention.</td>
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<th>What does the standard mean for the organisation?</th>
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<tr>
<td>NHS boards:</td>
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<tr>
<td>• develop referral pathways and arrangements with a broad range of mental health and emotional wellbeing services</td>
</tr>
<tr>
<td>• ensure that staff have time to support and care for people</td>
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<tr>
<td>• review their service to ensure it is supportive and trauma-informed.</td>
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<tr>
<th>Examples of what meeting this standard might look like</th>
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<tbody>
<tr>
<td>• Feedback from people who experience services.</td>
</tr>
<tr>
<td>• Evidence of the use of routine screening for anxiety and depression using a validated measure.</td>
</tr>
<tr>
<td>• Documented risk strategy if someone presents as highly distressed or suicidal.</td>
</tr>
<tr>
<td>• Signposting to support group and peer-support for both the person with CHD and their families or representatives.</td>
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Standard 5: Fetal diagnosis

**Standard statement**

NHS boards have processes and pathways in place to support early diagnosis and effective management of fetal CHD.

**Rationale**

Diagnosing CHD in babies before they are born improves the outcomes for both mothers and babies.\(^{40, 41}\) When CHD is detected during pregnancy, the woman, and, where appropriate their partner, need to be provided with support throughout.\(^{42}\) Counselling and signposting to other organisations or support groups is good practice.\(^{43, 44}\)

Families need to be informed about their child’s prognosis and options before the birth to support effective planning. They should be part of a discussion about the location and mode of delivery. All teams must communicate effectively with one another and the pregnant women and partner, where appropriate. This may involve obstetrics, neonatology, general paediatrics and paediatric cardiology.

Support and education should be provided for obstetric sonographers who undertake screening. This can increase rate of early detection and accuracy of diagnosis.\(^{45}\) In the event of a diagnosis of fetal CHD, access to prenatal genetic screening should be available.

**Criteria**

**5.1** NHS boards, in collaboration with the national paediatric cardiology service, have agreed protocols for the care and treatment of all pregnant women with both standard and potential elevated risk of a fetal CHD diagnosis. It involves:

- fetal medicine units
- obstetric units
- neonatal units
- paediatric teams.

**5.2** All pregnant women with a standard risk of fetal CHD are offered a routine anomaly ultrasound scan between 18 and 21 weeks gestation to detect fetal cardiac conditions.
5.3 Pregnant women at high risk of fetal cardiac conditions, including those with a previous history of fetal CHD have timely access to:

- a fetal echocardiogram in their local area
- advanced scanning as required from the national fetal cardiology service
- prenatal genetic testing as required.

5.4 Each NHS board has a designated multidisciplinary team with:

- relevant expertise to identify fetal conditions
- access to specialist midwives to provide continuity of care
- responsibility for timely referral to the national fetal cardiology service.

5.5 NHS board have processes and protocols in place for prompt online referral to the national fetal cardiology service in all suspected cases of a fetal cardiac conditions, both structural and rhythm related.

5.6 Pregnant women are referred to the national fetal cardiology service and receive an urgent review within three working days of identification of a suspected or confirmed cardiac condition during a routine ultrasound examination.

5.7 NHS boards have access to high quality ultrasound equipment.

5.8 NHS boards provide person-centred support to pregnant women and, where appropriate, their partners, after confirmation of a fetal cardiac condition including:

- assessment for the need for referral to perinatal mental health or wellbeing support if required
- access to specialist nursing or midwifery support
- signposting to services or support groups
- signposting to the national CHD nurse specialist service
- the opportunity for shared decision making
- information and support about pregnancy options including termination counselling.

5.9 NHS boards implement the plan agreed between the pregnant woman, national fetal cardiac service and fetal medicine teams regarding the mode and location of delivery.
5.10 NHS boards provide women with confirmed fetal cardiac conditions with:

- ongoing routine maternity care
- access to specialist cardiac support including specialist nursing and fetal cardiology if required
- information regarding the proposed immediate cardiac management after delivery e.g. prostaglandin infusion, cardiac catheterisation or cardiac surgical intervention
- referral to paediatric cardiology after delivery, if required, in line with prenatal planning.

5.11 Staff make decisions about palliative care locally in conjunction with the parents or carers, the national fetal cardiology service, the local neonatal and paediatric teams and palliative care team as appropriate.

5.12 NHS boards ensure relevant staff can access:

- information and support about how and when to refer to the national fetal cardiology service through the online system
- protected time for training and professional development to improve early detection of fetal cardiac conditions
- national teaching and learning including membership of national professional networks
- training on particular genetic and chromosome conditions
- ongoing advice, support and feedback from the national fetal cardiology service.

5.13 All NHS boards have access to and use a consistent digital platform to share images, fetal or parental demographics, scan reports and correspondence related to maternity care in line with information governance protocols.

5.14 Ultrasound images and imaging studies are captured, stored, permanently archived and accessible on an electronic reporting system.
### What does the standard mean for pregnant women?

- You will be able to access high quality ultrasound scans in your area.
- If CHD is suspected, you will be able to access specialist scans, help and support as soon as possible.
- Your NHS board will work with you and the national service to design and put in place a plan that is right for you, including how you will be looked after during your pregnancy and where you will deliver your baby.

### What does the standard mean for staff?

**Staff:**
- involve and support pregnant women with suspected or confirmed fetal CHD
- can refer online to the national service when they suspect fetal CHD
- receive specialist training appropriate to roles and responsibilities to improve detection rates.

### What does the standard mean for the organisation?

**NHS Boards:**
- routinely provide high quality ultrasound to support early detection of CHD
- have referral pathways in place to support early intervention
- work in partnership with the national service to provide shared care for pregnant women with detected fetal CHD
- share information and images where required in line with established information governance protocols.

### Examples of what meeting this standard might look like

- Detection rates of fetal CHD.
- National clinical audit of CHD screening and fetal diagnosis.
- Documented referral pathways.
- Shared care plans including plans for mode and timing of delivery.
Standard 6: Outpatient care

Standard statement
NHS boards provide high quality outpatient care for people with CHD.

Rationale
Effective outpatient clinics facilitate recognition and early response to changes in a person’s condition through a discussion of symptoms and access to high quality diagnostics and monitoring.\(^{13,47}\) People should be empowered to understand changes in their condition and access clinics if they need them.

Digital systems and timely information sharing can support early response to changes in people’s condition.\(^{48}\)

Ongoing outpatient care should be provided as close to the person’s home as possible, depending on their circumstances. It should be delivered by a designated local link paediatrician or link adult cardiologist. Clinics should include access to a local congenital cardiac nurse, cardiac physiology and input from the relevant national service if required. Ideally, relevant tests or scans should be undertaken at a single visit to reduce travel and clinic times.

Criteria

6.1 People with CHD have access to a designated outpatient clinic, appropriate to their needs, which includes:

- ECG, echocardiography and phlebotomy
- baseline observation
- device interrogation and cardiac monitoring.

6.2 Staff working in outpatient clinics can access, as required:

- information and results of investigations
- effective and high quality IT systems
- equipment appropriate to the imaging needs of the clinic population
- facilities for archiving of echocardiogram images
- echocardiogram images from other services.
6.3 NHS boards ensure appropriate staff availability for a **paediatric** cardiology outpatient clinic including:

- support from a paediatric cardiologist
- delivery by a link paediatrician
- local congenital cardiac nurses with access to congenital cardiac nurse specialists
- administrative and support staff
- appropriately-trained cardiac physiology staff.

6.4 NHS boards ensure appropriate staff availability for an **adult** cardiology outpatient clinic including:

- a link adult cardiologist
- local congenital cardiac nurses with access to congenital cardiac nurse specialists and healthcare assistants
- administrative and support staff
- appropriately-trained cardiac physiology staff.

6.5 NHS boards ensure that clinic correspondence, including the outcome of discussions and results, is produced in a timely manner and shared with:

- the appropriate healthcare professionals
- the person with CHD and their family or representatives if requested.

6.6 NHS boards have facilities and systems in place to view relevant real-time clinical information from the national service, including appointment times.

6.7 Outpatient services take steps to identify barriers to access, support people to attend and proactively re-engage people who have been lost to follow up.

6.8 Individuals can re-access outpatient services if they move or choose to pause attendance.

6.9 People with CHD and where appropriate, their families or representatives, are given time and support to discuss their condition and raise any concerns they have.

6.10 NHS boards provide access to:

- rhythm monitoring
- radiology (CT or MRI) including for aortic conditions
- high quality imaging and reporting in line with national guidance
- referral pathways for complex imaging.
6.11 Link cardiologists and paediatricians can remotely join multidisciplinary team discussions with the national service as required.

<table>
<thead>
<tr>
<th>What does the standard mean for people with CHD?</th>
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<tbody>
<tr>
<td>• Your condition will be monitored through tests and scans to keep you safe and well.</td>
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<tr>
<td>• You will get the tests you need.</td>
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<tr>
<td>• Clinics and tests will be coordinated and planned between services.</td>
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<tr>
<td>• Staff have the skills and information they need to look after you.</td>
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<tr>
<th>What does the standard mean for staff?</th>
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<tr>
<td><strong>Staff:</strong></td>
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<tr>
<td>• have the right skills and training in aspects of CHD outpatient care</td>
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<tr>
<td>• can access information they need to detect and respond to changes in a person’s condition</td>
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<tr>
<td>• are able to support the person to make decisions about their own care</td>
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<tr>
<td>• are able to communicate and share information relating to the person’s care between other staff members and teams.</td>
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<th>What does the standard mean for the organisation?</th>
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<tr>
<td><strong>NHS boards:</strong></td>
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<tr>
<td>• ensure staff mix and levels meet the needs of their population</td>
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<tr>
<td>• provide access to high quality monitoring and imaging in as few appointments as possible</td>
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<tr>
<td>• ensure that clinically-relevant information, including scan images, can be shared between services.</td>
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<tr>
<th>Examples of what meeting this standard might look like</th>
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<tbody>
<tr>
<td>• Provision of same-day tests including echocardiograms.</td>
</tr>
<tr>
<td>• Shared and real-time clinical systems.</td>
</tr>
<tr>
<td>• Workforce planning and clinic staffing levels in line with safe staffing legislation.</td>
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<tr>
<td>• Clinic population needs assessments.</td>
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<tr>
<td>• Innovation and outreach to reduce inequalities of access.</td>
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Standard 7: Shared care

**Standard statement**

NHS boards ensure that people with CHD have access to appropriate specialist services, support and advice.

**Rationale**

Lifelong care requires effective communication and partnership working between services. Defined local and national roles and protocols ensure that people living with CHD are able to access the right care, from the right person, at the right time.

People with CHD have increased risk of associated conditions. Syndromic and genetic conditions such as Down’s syndrome are over-represented in the CHD population.\(^49\) People may have particular needs and comorbidities that require multidisciplinary input. NHS boards should ensure timely and convenient access to other specialist services and support services. They should offer holistic support and advice according to the person’s rights, choices and circumstances.

**Criteria**

7.1 People with CHD, and where appropriate, their families or representatives, are listened to and engaged in shared decisions about their care.

7.2 People with CHD have:

- high quality information that meets their communication or support needs
- a health records summary
- a clearly-defined care or management plan\(^13\) detailing the role of services and timing of appointments.

7.3 NHS boards ensure that there is:

- sharing of expertise and advice between services
- effective discharge planning
- planned transfer of care between the national and local service.

7.4 NHS boards have clear referral pathways from primary care to CHD services.

7.5 Staff signpost or refer to third sector and other services with the person’s informed consent.

7.6 People with CHD are offered cardiac rehabilitation that meets their needs and goals.
### What does the standard mean for people with CHD?

- You are listened to, involved and share in decision making relating to your care and support.
- You are informed about your care in a way that is right for you.
- Services work together to support you.
- You can be confident that the people involved in your care work effectively together and with your usual specialist care team when needed.

### What does the standard mean for staff?

**Staff:**

- work across services to care of for people with CHD
- have knowledge of, and are able to refer to, specialist services
- are able to support people living with CHD by listening to them and helping them to make decisions in partnership
- are able to share information and expertise between health professionals, teams and services.

### What does the standard mean for the organisation?

**NHS boards:**

- ensure that pathways and processes are well-coordinated and facilitate shared care
- develop processes for information sharing between teams, professionals and those receiving care
- work together with agencies, including third and independent sector, to support the continuity of care and support.

### Examples of what meeting this standard might look like

- Referral pathways from primary care.
- Networks, learning systems and joint improvement work.
- Use of tools and support materials to facilitate shared decision making.
- Data flow, information sharing agreements and integrated systems.
Standard 8: Transition between paediatric and adult services

Standard statement
NHS boards ensure that people with CHD experience seamless and person-centred transition between paediatric and adult services.

Rationale
People with CHD move between paediatric and adult services as they grow up. The process for transition should start before the person is 14 years old. The exact timing may be determined by personal circumstances and choice. \(^{50}\) Ongoing care, including plans for unscheduled care, must continue during the process. The wishes of the child and their family or representatives should be central to planning. They should be actively involved in planning and be listened to and taken seriously. \(^{29,51}\)

The transition process should involve a link paediatrician, a link adult cardiologist and a local congenital cardiac nurse. A close working relationship between local and national paediatric and adult services is essential for smooth and effective transition. It supports overall positive outcomes for those living with CHD. Clinically relevant information and records should be kept throughout the process. Established protocols and legislation govern how health data is accessed and shared.

Criteria

8.1 NHS boards ensure that there is:
- a robust, seamless and documented transition process between paediatric and adult services, involving the national service where required
- a transition clinic
- time for individual consultation with the person with CHD and where appropriate, their family or representatives, at the time of transition.

8.2 NHS boards ensure that the transition process is supported by the involvement of:
- the person with CHD and where appropriate their family or representatives
- a local congenital cardiac nurse
- an adult link cardiologist
- a link paediatrician
- specialist organisations that meet a person’s particular needs.
8.3 The timing of transition is based on the person’s choice and circumstances and begins before they are 14 years old.

8.4 Staff develop a person-centred transition care plan which is:
   - led by the person and their representative
   - informed by the person’s needs and desired outcomes
   - reviewed as needs change
   - documented and shared with relevant services and the person where appropriate.

8.5 People with CHD are involved in discussions about who their transition plan is shared with and how.

8.6 People with CHD and where appropriate their family or representatives have access to:
   - general lifestyle advice, support and signposting to external agencies (including peer support)
   - preconception, sexual health and contraception counselling advice and support
   - psychological support and referral.

8.7 Staff support people with CHD to self-manage their condition taking into account personal choice and circumstances.

8.8 People with CHD have an agreed plan for unscheduled care during transition.

8.9 NHS boards ensure that systems and pathways are flexible to meet the needs and rights of young people who may require unscheduled care during transition.

What does the standard mean for people with CHD?

- You will move to the adult CHD service at a time that is right for you.
- The transition will be planned and supported and you will be included in this process.
- Your thoughts and what matters to you will be important.
- You will get information in a way that is right for you.
- Your condition will be monitored and you will be looked after during the transition.
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<th>What does the standard mean for staff?</th>
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<tr>
<td><strong>Staff:</strong></td>
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<tr>
<td>• plan transition between paediatric and adult services with input from relevant specialties</td>
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<tr>
<td>• listen to and involve people and where appropriate their families and representatives</td>
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<tr>
<td>• are able to signpost people to the most current information and refer to support services appropriate to their needs.</td>
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<tr>
<td><strong>NHS boards:</strong></td>
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<tr>
<td>• create a documented transition process for people with CHD</td>
</tr>
<tr>
<td>• demonstrate close working relationships between local and national paediatric and adult services</td>
</tr>
<tr>
<td>• ensure that staff are supported to provide the right care, support and signposting to people with CHD during transition.</td>
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<tr>
<th>Examples of what meeting this standard might look like</th>
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<tbody>
<tr>
<td>• Documented transition process.</td>
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<tr>
<td>• Individual and accessible transition plans.</td>
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<tr>
<td>• Children and young people’s involvement in the design of transition processes and information resources.</td>
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<tr>
<td>• Support and peer groups for children and their families or representatives.</td>
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Standard 9: Preconception and pregnancy care

**Standard statement**

Women with CHD who may become pregnant receive preconception care, counselling and specialist pregnancy care.

**Rationale**

Cardiovascular disease is the leading cause of maternal death in the UK. This risk can extend beyond the pregnancy. Women from Black and Asian ethnic backgrounds or from lower socioeconomic backgrounds are at higher risk of maternal death, stillbirth and neonatal mortality.

Women with CHD are more likely to have menstrual cycle disorders which can result in infertility or miscarriage. Support should be given to people with CHD exploring adoption or infertility treatment.

Women’s risk during pregnancy is categorised by modified World Health Organization maternal classification (mWHO). Using international classification supports NHS boards to identify relevant pathways and manage risk, sharing learning from elsewhere. Women in mWHO risk class II–III, III and IV, should be cared for by a multidisciplinary pregnancy heart team. This includes a cardiologist and obstetrician. It may also include specialists in genetics or sexual and reproductive health. Obstetric pathways should take account of local, regional, and national expertise. All pregnant women with CHD should have access to a local congenital cardiac nurse.

Preconception care and counselling supports people to make informed choices about their future. It can improve general pregnancy health and cardiovascular status. Pregnant women should be informed about their risk as soon as possible. Plans to manage risk during pregnancy or delivery include anticoagulation, pharmaceutical review and anaesthetics.

Both women and men with CHD should be offered information about safe, effective contraception. They should be informed about the risk of cardiovascular disease in their children. This information should be provided by a healthcare professional with knowledge in obstetric cardiology.
Criteria

9.1 NHS boards ensure that women with CHD who may become pregnant are routinely provided with:
   - contraceptive advice and preconception care including advice to take folic acid
   - specific CHD preconception counselling relevant to their risk
   - ongoing reassessment if medication is reduced or stopped.

9.2 Staff undertake holistic and validated risk assessments of women with CHD who may become pregnant, which considers:
   - their cardiovascular status
   - co-morbidities
   - obstetric history
   - social factors that could impact maternal and fetal outcomes.

9.3 Each NHS board has established referral and escalation pathways that include the national service for women with complex or high risk CHD requiring preconception counselling and pregnancy management.

9.4 NHS boards ensure that women who may become pregnant are offered preconception counselling as indicated which may include:
   - assessment and counselling by a cardiologist and/or obstetrician with expertise in cardiac obstetric care
   - access to a local congenital cardiac nurse to support the person’s pathway
   - information and counselling on the risk of CHD recurrence and/or inheritance in their baby.

9.5 Women who may become pregnant receive as indicated:
   - information on the maternal and fetal implications of anticoagulation during pregnancy, in partnership with a haematologist where relevant
   - a plan for anticoagulation, developed in partnership with a haematologist.
9.6 Women who may become pregnant have access to advice and information relating to all family planning options including:

- emergency and long acting contraception
- risks associated with medication withdrawal or assessment
- risk associated with stopping contraception during medication withdrawal or assessment
- benefits and implications of assisted reproductive technologies
- processes for adoption and how CHD can influence the outcome
- supporting the decision not to have a family.

9.7 Women are supported as early in pregnancy as possible to make informed choices, including where appropriate, whether to continue a pregnancy.

9.8 Pregnant women with complex or high risk CHD, based on mWHO classification:

- are provided with a joint obstetric and cardiology care plan which includes information on the frequency of assessment and review to meet maternal and fetal needs
- have access to a multi-disciplinary team including CHD cardiologists, obstetricians and anaesthetists, relevant to their care plan
- have access to echocardiography as required.

9.9 Pregnant women with CHD have an individual care plan which:

- involves them and where appropriate their family or representatives
- is reviewed and updated continuously as things change
- is shared between NHS boards, specialist services and all health professionals involved in ongoing care.

9.10 NHS boards offer detailed fetal echocardiography when either biological parents have CHD.

9.11 NHS boards ensure staff:

- recognise when pregnant women with CHD present with change in cardiovascular status
- facilitate timely investigations to assess change in cardiac status and prioritise pregnant women as appropriate
- facilitate appropriate assessment, investigation and referral to a consultant obstetrician and/or cardiologist where required
- support and signpost pregnant women with CHD who require psychological support.
9.12 Following pregnancy, women with CHD have access to:

- pre-discharge contraception within the principles of informed choice
- ongoing cardiology review.

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<thead>
<tr>
<th>What does the standard mean for people with CHD?</th>
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<tr>
<td>• You will be fully informed about what may happen if you become pregnant to support you to make decisions about your future.</td>
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<tr>
<td>• You will be supported to make the right choice for you and your family.</td>
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<tr>
<td>• Your risk in pregnancy will be assessed and shared with you.</td>
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<tr>
<td>• The team that looks after you when you are pregnant will be highly trained and specialist.</td>
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<tr>
<td>• You will be cared for and monitored throughout your pregnancy.</td>
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<th>What does the standard mean for staff?</th>
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<tr>
<td>Staff:</td>
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<tr>
<td>• work in partnership to keep pregnant women with CHD safe</td>
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<tr>
<td>• provide advice and support to women with CHD who may become pregnant</td>
</tr>
<tr>
<td>• know who to go to for specialist advice and when to refer to the national service</td>
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<tr>
<td>• support people’s choices about their future.</td>
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<th>What does the standard mean for the organisation?</th>
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<tr>
<td>NHS boards:</td>
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<tr>
<td>• provide high quality local antenatal and postnatal support for pregnant women with CHD where it is safe to do so</td>
</tr>
<tr>
<td>• have protocols and referral pathways in place to ensure safe care for pregnant women with CHD</td>
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<tr>
<td>• share information, skills and expertise when needed.</td>
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<tr>
<th>Examples of what meeting this standard might look like</th>
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<tbody>
<tr>
<td>• Assessment and documentation of risk in line with mWHO guidance.</td>
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<tr>
<td>• Evidence of multidisciplinary working as a pregnancy heart team, including team meetings and information sharing.</td>
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<tr>
<td>• Clinical audit and case review.</td>
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<tr>
<td>• Escalation and risk protocols.</td>
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Standard 10: Emergency care

Standard statement
NHS boards ensure that emergency care for people with CHD is safe and effective.

Rationale
Access to information enables safe and effective care for people in emergency departments. This is enhanced by shared digital systems containing up-to-date information. Information about a person’s diagnosis, interventions and drug treatment should be available at all times across and between all NHS boards.

Access to up to date scans and tests, including echocardiograms and device monitoring, facilitates timely treatment and diagnosis. This enhances patient safety in high risk emergency situations. Immediate and easy access to congenital cardiology advice should be available. Remote, real-time, review of echocardiograms and ECGs facilitates safe care of newborn infants with suspected CHD and minimises unnecessary transfers. Effective and timely referral pathways from emergency departments to the national service are essential for patient safety.

Criteria

10.1 Each emergency department can access immediate up-to-date clinical information about people with CHD from all NHS boards and services including the national service.

10.2 Each emergency department is provided with nationally consistent and immediately accessible information on how and when to access specialist advice including from the national service if required.

10.3 Each emergency department, including the maternity assessment unit, has clearly defined protocols for referral and escalation which provide information on:

- out of hours access
- guidance for referrals
- local, regional and national services
- roles and responsibilities including key decision makers
- care pathways specific to paediatric and neonatal cases
- emergency non-cardiac presentations requiring anaesthetic or obstetric input.
10.4 NHS boards have guidance for the recognition and care of pregnant women with CHD attending maternity assessment units or emergency departments.

10.5 High quality imaging including echocardiograms can be accessed and shared in a timely manner across all NHS boards and services, including the national service.

10.6 NHS boards have processes and referral pathways in place to facilitate out of hours management of:

- safe care of people with suspected heart rhythms emergencies
- the management of people with cardiac devices.

10.7 Key information summaries for people with CHD are available to ambulance staff and emergency department staff.

10.8 People with CHD are signposted to an identifiable marker including clinical alerts or medical information bracelets where appropriate.

10.9 People with CHD have an emergency care plan, if required, which:

- is immediately accessible and shared electronically
- is held individually
- is developed in partnership with their specialist team and shared with the person
- includes emergency contact details
- is accessible by all emergency departments
- highlights additional needs including communication needs
- details their wishes and preferences in relation to resuscitation.

10.10 People with CHD who receive emergency care and their families or carers are offered inclusive information in a format and language that is right for them about:

- their rights
- the rights of their families or representatives
- feedback and complaints procedures
- who to talk to if they have any concerns about their health once they have been discharged
- support organisations or groups they can talk to about their experience.
10.11 NHS boards provide staff in emergency departments with:

- key resources including condition- and patient-specific information in a timely manner
- training, relevant to their roles and responsibilities, about potential risks and safety protocols for people who have CHD
- information on how and when to access local and national specialist information and support
- training relevant to their roles and responsibilities on the specific needs of people with chromosome-related conditions who have CHD.

10.12 Information on a person’s presentation to emergency departments is proactively shared with relevant staff on discharge, to support onward planning and support.

**What does the standard mean for the person receiving care?**

- Staff in emergency departments are aware of your condition and how to safely look after you.
- Important information about you is immediately available to people who need it.
- You will be listened to by healthcare professionals and your experience of living with your condition will be acknowledged.
- You will receive accessible information about your experience in an emergency department and what will happen next.

**What does the standard mean for staff?**

**Staff:**

- have immediate access to anticipatory care plans
- receive immediate clinical information about people with CHD who present in emergency departments
- know when and how to access specialist support or advice, including from the national service.

**What does the standard mean for the organisation?**

**NHS boards:**

- have established pathways and procures for emergency departments to ensure safe, effective and person-centred care of people with CHD
- work collaboratively to share relevant information
- develop, improve and update systems to ensure immediate access to clinical information.
### Examples of what meeting this standard might look like

- Consistent guidance or clinical pathways for emergency care.
- Local decision-making charts and procedures.
- Shared digital systems.
- Agreed referral pathways, documentation on escalation procedures and safety planning.
Standard 11: Palliative care and bereavement

**Standard statement**
NHS boards provide high quality and compassionate palliative and bereavement care.

**Rationale**
Palliative care is a crucial part of integrated, people-centred health services. It is recognised under people’s international right to health. Palliative care improves the quality of life of people who are affected by life-threatening or life-limiting illness. For particular congenital conditions, ongoing assessment and anticipatory care planning should be provided from an early age. Meaningful conversations should take place with the person with CHD, and where appropriate their families or representatives, throughout their life. These conversations should take place in the context of the person’s cultural or religious beliefs. People with learning disabilities or additional needs may need support to understand what may happen. A range of services should be involved to meet people’s specific needs at the end of their life.

**Criteria**

11.1 People with CHD are fully informed about what their future quality of life may be and are involved in ongoing discussions about their prognosis.

11.2 People with CHD are involved in anticipatory care planning and conversations about palliative care that:

- are held early in their journey
- are appropriately timed
- support and empower them to live their life
- involve professionals with whom they have an ongoing relationship
- are supportive and compassionate
- meet their social, communication and cultural needs, including the use of signing or Easy Read information.

11.3 Families or representatives of people with CHD are involved in discussions where appropriate, and supported.
11.4 Each NHS board provides access to palliative care and referral pathways to specialist palliative care involving, as required:

- third sector support
- perinatal bereavement support services as appropriate
- a local congenital cardiac nurse
- specialist nursing teams such as heart failure specialist nursing
- clinical psychology
- primary care.

11.5 NHS boards ensure robust and effective communication between services during anticipatory care planning and at the point of death, including ongoing bereavement support.

11.6 When death occurs, either expected or unexpected, NHS boards have protocols and policies in place in line with national guidance to ensure:

- joint child death review, including input from families and carers
- a designated lead or key contact for overseeing the review process and a key contact for families and carers
- notification to local cardiac services and other relevant services
- access to post mortem and written report
- multidisciplinary learning and review processes as required.

11.7 In the instance of a child’s death:

- families and carers can access an independent key contact for information and support
- there is a joint child death review, including input from families and carers.

11.8 Each NHS board has established pathways for bereavement support for the families and carers of people with CHD throughout their life.

11.9 NHS boards provide bereavement education, training and support for staff including peer support and signposting to support services if required.
### What does the standard mean for people with CHD?

- Staff talk to you and the people important to you about how you can expect your condition to develop in the future.
- You are involved and listened to in discussions about how to manage your condition in the future.
- Your care towards the end of your life upholds your rights and provides you with dignity, compassion and respect.
- Your family and carers get the support they need when you die.

### What does the standard mean for staff?

**Staff:**

- are trained and skilled to talk about end of life care and bereavement
- are involved in compassionate discussions about palliative care at the right time
- know how to refer to specialist palliative care services if they need them
- are supported as needed when patients die.

### What does the standard mean for the organisation?

**NHS boards:**

- have effective referral pathways for palliative and end of life care for people with CHD
- provide training and support to staff working in palliative care and following bereavement
- provide information required as part of child death reviews
- ensure people who are dying are treated with respect, dignity and compassion.

### Examples of what meeting this standard might look like

- Referral pathways to specialist palliative and end of life care.
- Provision of specialist nursing, including a local congenital cardiac nurse.
- Documented anticipatory care plans shared between services and relevant professionals, including primary care.
Appendix 1: Development of the congenital heart disease standards

The congenital heart disease standards have been informed by current evidence, best practice recommendations and developed by group consensus.

Evidence base

A systematic review of the literature was carried out using an explicit search strategy devised by an Evidence and Information Scientist from the Research and Information Service. Databases searched include Medline, Embase, Cinahl, PsycINFO and the Cochrane Library. The year range covered was 2000-2022. Internet searches were carried out on various websites. The results were summarised and presented to the standards development group. The main searches were supplemented by material identified by individual members of the development group.

At the start of the standards development process, a literature search was carried out to identify qualitative and quantitative studies that addressed patient issues of relevance to the delivery of CHD services. Databases searched include Medline, Embase, Cinahl and PsycINFO.

Standards development

Each standard is underpinned with the views and expectations of health care staff, third sector representatives, people accessing the service and the public in relation to CHD. Information has been gathered from a number of sources and activities, including development group meetings and a consultation survey on the draft scope.
Consultation feedback and finalisation of standards

Following consultation, the standards development group will reconvene to review all comments received and make final decisions and changes. More information can be found in the consultation feedback report which will be available on the Healthcare Improvement Scotland website.

Quality assurance

All development group members were responsible for advising on the professional aspects of the standards. Clinical members of the development group advised on clinical aspects of the work. The co-chairs had lead responsibility for formal clinical assurance and sign off on the technical and professional validity and acceptability of any reports or recommendations from the group.

All development group members made a declaration of interest at the beginning of the project. They also reviewed and agreed to the development group’s terms of reference. More details are available on request from his.standardsandindicators@nhs.scot.

The standards were developed within the Operating Framework for Healthcare Improvement Scotland and the Scottish Government (2022), which highlights the principles of independence, openness, transparency, and accountability.

For more information about Healthcare Improvement Scotland’s role, direction and priorities, please visit: www.healthcareimprovementscotland.org/
## Appendix 2: Membership of the Standards Development Group

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patrick Gibson (Co Chair)</td>
<td>Consultant Cardiologist</td>
<td>NHS Lothian</td>
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<tr>
<td>Patrick Noonan (Co Chair)</td>
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<td>NHS Greater Glasgow and Clyde</td>
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<tr>
<td>Carla Benedetti</td>
<td>Cardiac Nurse Specialist Coordinator</td>
<td>NHS Greater Glasgow and Clyde</td>
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<td>Susan Cassidy</td>
<td>Cardiac Clinical Psychologist</td>
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</tr>
<tr>
<td>Louise Chapman</td>
<td>Echo Physiologist, ACHD Services</td>
<td>NHS Grampian</td>
</tr>
<tr>
<td>Peter Currie</td>
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<tr>
<td>Joanne Cusack</td>
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<tr>
<td>Adelle Dawson</td>
<td>Consultant Cardiologist</td>
<td>NHS Grampian</td>
</tr>
<tr>
<td>Frances Divers</td>
<td>Cardiology Nurse Consultant and Clinical Champion for Cardiac Rehabilitation for SG</td>
<td>NHS Lothian and Scottish Government</td>
</tr>
<tr>
<td>Emma Finlay</td>
<td>Lead Physiologist</td>
<td>NHS Greater Glasgow and Clyde</td>
</tr>
<tr>
<td>Richard Forsyth</td>
<td>Health Systems Insight Manager - Scotland</td>
<td>British Heart Foundation</td>
</tr>
<tr>
<td>Rebecca Goldman</td>
<td>Consultant Paediatrician</td>
<td>NHS Tayside</td>
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<tr>
<td>Keir Greenhalgh</td>
<td>Consultant Paediatrician</td>
<td>NHS Lanarkshire</td>
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<tr>
<td>Karen Hogg</td>
<td>Consultant Cardiologist</td>
<td>NHS Greater Glasgow and Clyde</td>
</tr>
<tr>
<td>Deirdre Holly</td>
<td>Principal Clinical and Health Psychologist</td>
<td>NHS Golden Jubilee National Hospital</td>
</tr>
<tr>
<td>Jo Hughes</td>
<td>Head of Service Development</td>
<td>Down’s Syndrome Scotland</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Organisation</td>
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<tr>
<td>Lindsey Hunter</td>
<td>Consultant Paediatric &amp; Fetal Cardiology</td>
<td>NHS Greater Glasgow and Clyde</td>
</tr>
<tr>
<td>Clare Irving</td>
<td>Consultant Paediatrician with special interest in CHD</td>
<td>NHS Borders</td>
</tr>
<tr>
<td>Vivien Jayne</td>
<td>Policy Officer</td>
<td>Down’s Syndrome Scotland</td>
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<tr>
<td>Vera Lennie</td>
<td>Consultant Cardiologist</td>
<td>NHS Ayrshire &amp; Arran</td>
</tr>
<tr>
<td>Stuart Lilley</td>
<td>Head of Paediatric Cardiac Physiology</td>
<td>NHS Greater Glasgow and Clyde</td>
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<tr>
<td>Joelle Miller</td>
<td>SACHD Secretary</td>
<td>Chest Heart and Stroke</td>
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<tr>
<td>Mel Miller</td>
<td>Programme Manager</td>
<td>National Services Division</td>
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<tr>
<td>Lynn Miller</td>
<td>Consultant Cardiologist</td>
<td>NHS Fife</td>
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<tr>
<td>Marion Morris</td>
<td>Senior Policy Manager</td>
<td>Scottish Government</td>
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<tr>
<td>Liza Morton</td>
<td>Counselling Psychologist and person with lived experience of CHD</td>
<td>Somerville Foundation</td>
</tr>
<tr>
<td>Elaine Muirhead</td>
<td>Senior Specialist Nurse</td>
<td>NHS Golden Jubilee National Hospital</td>
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<tr>
<td>Lesley O’Brien</td>
<td>Cardiac Rehabilitation Physiotherapist</td>
<td>NHS Lanarkshire</td>
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<tr>
<td>Ruther Pegler</td>
<td>Clinical Psychologist</td>
<td>NHS Greater Glasgow and Clyde</td>
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<tr>
<td>Lindsey Pope</td>
<td>GP and Professor of Medicine</td>
<td>University of Glasgow</td>
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<tr>
<td>Jane Ramsay</td>
<td>Consultant Obstetrician</td>
<td>NHS Ayrshire &amp; Arran</td>
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<tr>
<td>Jennifer Scotland</td>
<td>Consultant Paediatrician</td>
<td>NHS Tayside</td>
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<tr>
<td>Maggie Simpson</td>
<td>CHD Nurse Specialist</td>
<td>NHS Greater Glasgow and Clyde</td>
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<tr>
<td>Niki Walker</td>
<td>Consultant Cardiologist, clinical lead for Scottish Adult Congenital Cardiac Service</td>
<td>NHS Golden Jubilee National Hospital</td>
</tr>
<tr>
<td>Helen Zollinger</td>
<td>Parent of child with CHD</td>
<td>N/A</td>
</tr>
</tbody>
</table>
## Appendix 3: Membership of the CHD Standards Project Team

### Current Project Team Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
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<td>Rachel Hewitt</td>
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<td>Healthcare Improvement Scotland</td>
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<tr>
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<td>Silas McGilvray</td>
<td>Project Officer</td>
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<tr>
<td>Fiona Wardell</td>
<td>Team Lead, Standards and Indicators</td>
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</tbody>
</table>

### Previous Project Team Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karen Grant</td>
<td>Programme Manager</td>
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<tr>
<td>Tracey Mitchell</td>
<td>Project Officer</td>
<td>Healthcare Improvement Scotland</td>
</tr>
<tr>
<td>Paula O’Brien</td>
<td>Administrative Officer</td>
<td>Healthcare Improvement Scotland</td>
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</tbody>
</table>
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1. NHS. Congenital Heart Disease. 2021 [cited 2023 Apr 27]; Available from: https://www.nhs.uk/conditions/congenital-heart-disease/#:~:text=Congenital%20heart%20disease%20is%20a,babies%20born%20in%20the%20UK.
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