



Healthcare  
Improvement  
Scotland

**Evidence**  
Advice, guidance  
and intelligence

# Congenital heart disease

---

Standards for local and regional services

November 2023

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 identity, 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](mailto:his.standardsandindicators@nhs.scot) to notify us of any updates that might require consideration.

## **Healthcare Improvement Scotland 2023**

**Published November 2023**

This document is licensed under the Creative Commons Attribution-Noncommercial-NoDerivatives 4.0 International Licence. This allows for the copy and redistribution of this document as long as Healthcare Improvement Scotland is fully acknowledged and given credit. The material must not be remixed, transformed or built upon in any way. To view a copy of this licence, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/>

**[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)**

# Contents

Contents	3
Introduction	4
Summary of standards	8
Standard 1: Leadership and governance	9
Standard 2: Person-centred care and shared decision-making	13
Standard 3: Staff education and training	16
Standard 4: Mental health and emotional wellbeing	19
Standard 5: Fetal diagnosis	23
Standard 6: Outpatient care	28
Standard 7: Shared care	31
Standard 8: Transition between paediatric and adult services	33
Standard 9: Preconception and pregnancy care	36
Standard 10: Emergency care	41
Standard 11: Palliative care and bereavement	45
Appendix 1: Development of the congenital heart disease standards	48
Appendix 2: Membership of the Standards Development Group	50
References	52

# 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 eight in every 1,000 babies born in the UK.<sup>1</sup> 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.<sup>2</sup> The number of babies and children with CHD living to adulthood has increased by approximately 75% over the last 60 years.<sup>3</sup> 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 two services are commissioned by NHS National Services Division (NSD) on behalf of the Scottish Government. They are known as either the paediatric or adult 'national service.' Additional services for lifelong support and care are provided by local NHS boards.

## Policy context

In 2012, a public petition<sup>4</sup> 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). Standards for the two national services are monitored and implemented on an ongoing basis.<sup>5</sup>

In 2021 [the Heart Disease Action Plan \(Scotland\)](#) made explicit reference to improving care for the growing population of people with CHD.<sup>2</sup> 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.<sup>6</sup>
- United Nations Convention on the Rights of the Child.<sup>7</sup>
- United Nations Convention on the Elimination of Discrimination Against Women.<sup>8</sup>
- United Nations Convention on the Rights of Disabled People.<sup>9</sup>
- General Comment No. 22 from the UN Committee on Economic, Social and Cultural Rights.<sup>10</sup>

## Scope of the standards

These Healthcare Improvement Scotland standards are for all NHS boards across Scotland where people receive lifelong care outside the national services. The 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. Services may use these standards as a way to plan and measure improvement. 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.

Shared care between NHS boards and the national services is a key component of CHD care. While delivery of the standards rests with NHS boards, the journey to full implementation of these standards requires building on existing shared care mechanisms. The QMS Framework highlights the role of clear vision, leadership and collaboration at all levels to plan and deliver improvement and redesign.

## Terminology

Wherever possible, we have 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** includes a family member, friend, independent advocate or agreed person who can speak on the person's behalf. A representative may have power of attorney or be a legal guardian. A representative may be formal or informal.

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

The term **pregnant women/people** is used in relevant standards to refer to people, including trans and non-binary people, who are pregnant. **Maternity** and **maternal** is used in relevant clinic contexts to refer to the service and care delivered before and during pregnancy. It is also used in clinical contexts to refer to pregnant women/person in relation to genetic testing.

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 local 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.

# Summary of standards

## **Standard 1: Leadership and governance**

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

## **Standard 2: Person-centred care and shared decision-making**

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

## **Standard 3: Staff education and training**

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

## **Standard 4: Mental health and emotional wellbeing**

NHS boards provide a compassionate and understanding CHD service and ensure people with CHD can access support if they need it.

## **Standard 5: Fetal diagnosis**

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

## **Standard 6: Outpatient care**

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

## **Standard 7: Shared care**

NHS boards ensure that people with CHD have access to seamless interspecialty care.

## **Standard 8: Transition between paediatric and adult services**

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

## **Standard 9: Preconception and pregnancy care**

Women/people with CHD who may become pregnant receive preconception care, counselling and specialist antenatal care.

## **Standard 10: Emergency care**

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

## **Standard 11: Palliative care and bereavement**

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. NHS boards must oversee the whole CHD care pathway, from fetal diagnosis to ongoing treatment and care.<sup>11</sup> This requires the use of data to measure and plan improvement. Nominated lead clinicians for both paediatric and adult services provide essential oversight and assurance.

NHS boards have responsibility for clinical and care governance of all NHS services, including local CHD services. Good clinical and care governance includes adhering to guidelines and policies for adverse events management, whistleblowing, escalation procedures and data monitoring.<sup>12, 13</sup> This leads to better patient safety and improved clinical outcomes.

People with CHD and their families/representatives are an integral part of the design and monitoring of services.<sup>14</sup> Feedback allows NHS boards and services to plan improvements based on what matters to people. Implementation of the health and social care standards in all services upholds people's rights to compassionate, safe and person-centred care.<sup>15</sup>

## 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
  - transition between paediatric and adult services.

- 1.4** NHS boards participate annually in a national joint adult and paediatric CHD steering group. The group is responsible for:
- reviewing the quality and effectiveness of CHD services
  - implementation of the HIS CHD standards
  - sharing and acting on learning from quality improvement activities
  - use of data to monitor performance and improvement.
- 1.5** NHS boards have systems and processes to demonstrate:
- 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:
- details of the person 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 have systems and processes to demonstrate adherence to national whistleblowing standards.<sup>16</sup>
- 1.8** 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/representatives from all backgrounds.
- 1.9** NHS boards have pathways in place to ensure that people with CHD have access to:
- a local congenital cardiac nurse
  - psychological support from a psychologist with specialist knowledge of long-term physical health conditions
  - cardiac rehabilitation for adults with CHD.<sup>17</sup>
- 1.10** People living with CHD have the option of care close to home or the most accessible service for them.

**1.11** 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/representatives.

**1.12** NHS boards work in collaboration with the national services to collect and share data as required to support national benchmarking and research.

### What does the standard mean for people with CHD?

- You can be part of the design and monitoring of the CHD service if you want to be.
- You can be confident that the CHD service monitors and reviews its performance to keep improving.
- Staff work together to provide you with a high quality service.
- You will be listened to and taken seriously if you have any concerns about the service.
- 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.

### What does the standard mean for the NHS board?

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 the representation on a national steering group such as terms of reference.
- 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.<sup>18</sup> Person-centred care involves people, their families/representatives and services working together in partnership.<sup>19</sup> It is based on each individual's personal goals, preferences and needs.<sup>20</sup> This results in more effective care with better outcomes for people living with CHD.<sup>11</sup>

Being part of discussions and decisions about their care requires people to be fully informed and taken seriously.<sup>21</sup> People can be empowered when they are supported to make decisions about what matters to them.<sup>15</sup> 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. Information and discussions should be delivered in a way that is inclusive of people with learning or developmental disabilities.

## 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/representatives of people with CHD are fully informed and involved in discussions and decisions, where appropriate.
- 2.4** People with CHD have:
  - high quality information that meets their communication or support needs
  - a summary of their medical history and care plan
  - 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
  - discuss any aspect of their condition with enough time and support
  - raise questions or concerns
  - provide feedback on their care and experiences.
- 2.6** NHS boards provide people with CHD (and their families/representatives, where appropriate) with:
- information and support that is relevant to their language, age, understanding, circumstances and diagnosis
  - information about the service, including who to contact and how to arrange appointments
  - contact details of relevant health professionals
  - contact details of relevant third sector or support services.
- 2.7** People with CHD (and their families/representatives, where appropriate) receive:
- signposting to 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, listened to and taken seriously.
- 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.

## What does the standard mean for staff?

### Staff:

- support and listen to people with CHD
- actively engage with people to understand their needs and preferences
- understand that people are affected by CHD in different ways and offer appropriate support that reflects individual needs and preferences
- can support people (and their families/representatives where appropriate) to reach informed decisions in partnership with their healthcare professionals
- signpost people to current information and support appropriate to their needs.

## What does the standard mean for the NHS board?

### NHS boards:

- have systems and processes to ensure they deliver responsive care and support
- ensure the availability of appropriate, easily accessible and timely information and support
- have mechanisms to record and act upon feedback from people and their families/representatives
- ensure that staff have time and resources to support and care for people.

## Examples of what meeting this standard might look like

- Evidence of information provided in alternative formats and languages, taking account of the needs of people who may be digitally excluded.
- Clinical audit of CHD consultations with documentation of signposting or written information being provided.
- Evidence of patient involvement in decision making, tools for shared decision making, and effective communication.
- Ongoing engagement and support for people with CHD and their families/representatives.
- Evidence of any changes made based on feedback received.
- Evidence of support for people with additional communication needs, for example, people with sensory impairments or difficulties with speech and language.
- Signposting and supporting people to access other support services.
- Documentation relating to decision-making, feedback questionnaires and other communication methods relating to care plans.

# 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.<sup>22</sup> CHD is a complex condition and people often experience additional health and wellbeing challenges associated with it.<sup>23, 24</sup> Sensitive and compassionate staff understand and respond appropriately to people who may have experienced psychological trauma related to their health experiences.<sup>25, 26</sup>

Any staff across the health and social care system may provide care to people with CHD. As people with CHD are a growing population group, specific future workforce planning is required.<sup>27</sup> 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 undergraduates and postgraduates in medicine, nursing, midwifery, healthcare science 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:
- cardiology
  - obstetric cardiology
  - neonatal and paediatric services
  - allied cardiac services
  - anaesthetics
  - 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 CHD care have adequate training on aspects specific to the CHD population including:
- equalities and rights including communication needs
  - psychological, emotional and cognitive impact of cardiac conditions
  - 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 an understanding of the person's condition
  - compassionate staff who take time to understand and respect their wishes and personal outcomes.
- 3.8** Staff have access to peer support and supervision to:
- prevent or respond to and understand challenging situations
  - continue to provide high quality person-centred care.

### What does the standard mean for people with CHD?

- You are treated with dignity and compassion.
- The team who look after you are trained, skilled, knowledgeable and competent.

### What does the standard mean for staff?

Staff:

- can demonstrate knowledge, skills and competence relevant to their role and responsibilities
- attend and participate in relevant training
- receive support for their own mental health and emotional wellbeing
- receive accurate and current information to enable them to support people
- share knowledge and expertise about CHD with health professionals in training.

### What does the standard mean for the NHS board?

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 staff 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 compassionate and understanding 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.<sup>24, 28</sup> Up to 50% of people with CHD are diagnosed with anxiety, depression or post-traumatic stress disorder in their lifetime.<sup>29</sup> People with CHD often have neurocognitive difficulties or disabilities which affect executive function, memory, language and communication.<sup>30, 31</sup>

Serious illness is an adverse childhood experience.<sup>32, 33</sup> Frequent hospital stays and medical interventions can be traumatic and distressing for children and families.<sup>34, 35</sup> Disruption to early attachment can affect children's behaviour and social cognition.<sup>35, 36</sup>

Children with cardiac conditions may be more withdrawn, engage in fewer activities and struggle socially. Older children and adolescents are at risk of developing significant psychological difficulties such as anxiety and depression.<sup>36</sup> Parents and families of children with CHD often require support for their own mental health.<sup>37, 38</sup>

Adults with CHD, particularly people who were diagnosed many years ago, may require enhanced support which takes into account their historical experience of care.<sup>39</sup>

Psychologically informed services understand and mitigate distress, fear, anxiety and trauma associated with medical intervention.<sup>25</sup> Services that promote wellbeing and psychological safety can reduce health inequalities and improve outcomes.<sup>25</sup> Understanding and acknowledging the experiences of people who have experienced trauma can help services improve for everyone.<sup>40, 41</sup>

## Criteria

- 4.1** NHS boards have established referral pathways to specialist mental health and support services for people with CHD, including third sector and peer support services.
- 4.2** NHS boards follow action plans to meet quality frameworks for trauma-informed care.<sup>40</sup>
- 4.3** Staff use validated screening tools to assess the mental health and wellbeing of people with CHD and, where appropriate, their families/representatives.
- 4.4** People with CHD, and where appropriate their families/representatives, 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 of referral.<sup>42</sup>
- 4.5** Children and young people have access to mental health and wellbeing support including:
  - clinical or practitioner psychology
  - age and stage appropriate therapeutic support such as play specialists whole family support.
- 4.6** People with CHD are informed about options for continuous or ongoing support for their mental health and emotional wellbeing, including unscheduled mental health support.
- 4.7** People with CHD, and where appropriate, their families/representatives, can access support from a local congenital cardiac nurse, who can provide continuous emotional wellbeing support and advocacy.
- 4.8** People with CHD and their families/representatives can:
  - meet staff and see places or equipment before appointments, where possible
  - choose someone they know to be with them or nearby at appointments
  - discuss any concerns or anxiety that they may have before appointments or interventions.

**4.9** Families/representatives of people with CHD are offered:

- access to mental health support from a person with the appropriate skills and knowledge of people with lifelong physical health conditions
- physical contact with babies and children during hospital stays<sup>43</sup>
- signposting to relevant support organisations
- pre-emptive support at key stages of a person's life.

**4.10** Enhanced and tailored support as required is provided for people with social communication needs, learning disabilities or additional support needs.

**What does the standard mean for people with CHD?**

- Your mental health and emotional wellbeing will be prioritised throughout your care.
- Staff understand your experience and the impact it may have had on you.
- If you need support for your mental health or emotional wellbeing, you know where to go or who to turn to.

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

Staff:

- promote early attachment and bonding between babies and their parents or families
- know who to refer to if someone needs support
- recognise and respond to trauma associated with medical intervention
- receive support for their own mental health and emotional wellbeing.

**What does the standard mean for the NHS board?**

NHS boards:

- develop referral pathways and arrangements with a broad range of mental health and emotional wellbeing services
- ensure that staff have time to support and care for people and their families
- review their service to ensure it is supportive and trauma-informed.

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

- Actions taken as a result of feedback from people who experience services.
- Evidence of the use of routine screening for anxiety and depression using a validated measure.
- Documented risk strategy if someone presents as highly distressed or suicidal.
- Signposting to support group and peer-support for both the person with CHD and their families.

# 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.<sup>44, 45</sup> When CHD is detected during pregnancy, the person and, where appropriate, their partner need to be provided with support throughout.<sup>46</sup> Counselling from a qualified person and signposting to other organisations or support groups is good practice.<sup>47, 48</sup>

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 woman/person and their 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.<sup>49</sup> 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/people with both standard and elevated likelihood of a baby with CHD. This collaboration should involve:
- fetal medicine units
  - obstetric units
  - neonatal units
  - paediatric teams.
- 5.2** All pregnant women/people with a standard likelihood of having a baby with CHD are offered a routine anomaly ultrasound scan between 18 and 21 weeks gestation<sup>50</sup> to detect fetal cardiac conditions.

- 5.3** Pregnant women/people at an increased likelihood of a baby with a fetal cardiac condition, 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.<sup>51</sup>
- 5.4** NHS boards offer detailed fetal echocardiography when a biological parent has CHD.
- 5.5** 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.
- 5.6** NHS boards have processes and protocols in place for prompt online referral to the national fetal cardiology service in all suspected cases of fetal cardiac conditions, both structural and rhythm related.
- 5.7** Pregnant women/people are referred to the national fetal cardiology service and receive an urgent review within three working days of identification of a baby with suspected or confirmed cardiac condition during a routine ultrasound examination.<sup>51</sup>
- 5.8** NHS boards have access to safe and high quality ultrasound equipment.
- 5.9** NHS boards provide person-centred support to pregnant women/people and, where appropriate, their partners or families, after confirmation of a baby with fetal cardiac condition including:
- ongoing routine maternity and perinatal care
  - assessment for the need for referral to perinatal mental health, clinical or practitioner psychology or wellbeing support
  - 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
  - future care planning including bereavement support if required.



- 5.10** NHS boards implement the plan agreed between the pregnant woman/person, the national fetal cardiac service and fetal medicine teams regarding the mode and location of delivery.
- 5.11** NHS boards provide pregnant women/people with babies who have a confirmed fetal cardiac conditions with:
- access to specialist cardiac support including specialist nursing and fetal cardiology if required
  - information regarding the proposed immediate cardiac management after delivery including prostaglandin infusion, cardiac catheterisation or cardiac surgical intervention
  - referral to paediatric cardiology after delivery, if required, in line with prenatal planning.
- 5.12** Decisions about palliative care are made locally in conjunction with families/representatives, the national fetal cardiology service, the local neonatal and paediatric teams and palliative care team as appropriate.
- 5.13** 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.
- 5.14** 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 or perinatal care in line with information governance protocols.
- 5.15** Ultrasound images and imaging studies are captured, stored, permanently archived and accessible on an electronic reporting system in line with local information governance protocols.

### What does the standard mean for pregnant women/people?

- You will be able to access high quality ultrasound scans in your area to find out as early as possible if your baby has CHD.
- If your baby might have CHD, you will be able to access specialists as soon as possible.
- Staff will work with you to design and put in place a plan that is right for you.
- You will receive the support you need if a scan shows your baby has CHD.
- You will be looked after during your pregnancy by the right people at the right time.
- You will work with specialists to plan where and how you will deliver your baby.

### What does the standard mean for staff?

Staff:

- support and provide compassionate care to women/people who have confirmation of fetal CHD
- continue to provide ongoing routine, person-centred perinatal care
- work in partnership with the national services to plan for the delivery of babies with suspected or confirmed fetal CHD
- involve and support pregnant women/people 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 NHS board?

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/people 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 are improving.
- Referral pathways to specialist midwifery and obstetric services.
- Signposting and referral to support services including perinatal mental health and wellbeing services.
- 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. They provide an opportunity for people to discuss their symptoms and access high quality diagnostics and monitoring.<sup>11, 52</sup> People should be empowered to understand changes in their condition and access clinics if they need them.<sup>18</sup>

Digital systems and timely information sharing can support early response to changes in people's condition.<sup>53</sup>

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,<sup>54</sup> cardiac physiology<sup>55</sup> 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 assessed 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 echocardiogram images
  - echocardiogram images from other services.

- 6.3** NHS boards ensure necessary staffing to deliver 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 and healthcare assistants
  - administrative and support staff
  - appropriately-trained cardiac physiology staff.
- 6.4** NHS boards ensure necessary staffing to deliver 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 communication between outpatient clinics, 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/representatives if requested.
- 6.6** Outpatient services:
- identify barriers to access
  - support people to attend
  - proactively re-engage people who do not attend clinics.
- 6.7** Individuals are provided with information on how to transfer or re-access outpatient services if they move area or choose to pause attendance.
- 6.8** 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.

### What does the standard mean for people with CHD?

- You have dedicated time to discuss any concerns you have about your condition and any changes in your symptoms.
- You will get the tests you need.
- You will be fully supported to access clinics if you move area or pause attendance for any reason.
- Staff have the skills and information they need to look after you.

### What does the standard mean for staff?

Staff:

- have the right skills and training to support CHD outpatient care
- can access information they need to detect and respond to changes in a person's condition
- are able to communicate and share information relating to the person's care between other staff members and teams.

### What does the standard mean for the NHS board?

NHS boards:

- provide the required resources for a dedicated CHD outpatient clinic for their local population
- provide access to high quality monitoring and imaging in as few appointments as possible
- ensure that clinically-relevant information, including scan images, can be shared between services.

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

- Provision of same-day tests including echocardiograms.
- Shared and real-time clinical systems.
- Workforce planning and clinic staffing levels in line with safe staffing legislation.
- Clinic population needs assessments.
- Innovation and outreach to reduce inequalities of access.

# Standard 7: Shared care

## Standard statement

NHS boards ensure that people with CHD have access to seamless interspecialty care.

## Rationale

People with CHD have an increased risk of associated conditions. For example, syndromic and genetic conditions such as Down's syndrome are over-represented in the CHD population.<sup>56</sup> Access to dental care can reduce the risk of infective endocarditis.<sup>57</sup> Babies and children with CHD require specialist support to reduce the risk of malnourishment.<sup>58</sup> NHS boards should ensure timely and convenient access to other specialist services and support services.

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.

## Criteria

- 7.1 People with CHD have access to a clearly-defined care or management plan<sup>11</sup> detailing the role of services and timing of appointments.
- 7.2 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.
- 7.3 NHS boards, in partnership with the national service, provide access to paediatric dietetic advice specific to CHD.
- 7.4 NHS boards have clear referral pathways from primary care to CHD services.
- 7.5 Link cardiologists and paediatricians can remotely join multidisciplinary team discussions with the national service as required.
- 7.6 NHS boards have facilities and systems in place to view relevant real-time clinical information from the national service, including appointment times.
- 7.7 NHS boards ensure people with CHD can access twice yearly dental care, including follow-up as necessary.
- 7.8 People with CHD are offered cardiac rehabilitation that meets their needs and goals.

## 7.9 People with CHD are offered access to heart failure specialist nursing if required.<sup>17</sup>

### What does the standard mean for people with CHD?

- Services work together to support you.
- People who look after you have up-to-date information about you and your medical history.
- Where possible, clinic appointments and tests will be coordinated and planned between services.
- 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 for people with CHD
- have knowledge of, and are able to refer to, specialist services
- are able to share information and expertise between health professionals, teams and services.

### What does the standard mean for the NHS board?

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
- ensure 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.
- 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 a seamless and person-centred transition between paediatric and adult services.

## Rationale

Young 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 should be determined by personal circumstances and choice.<sup>59</sup> Ongoing care, including plans for unscheduled care, must continue during the process.<sup>60</sup> The wishes of the young person and their family/representatives should be central to planning.<sup>61</sup> Young people should be actively involved in planning and be listened to and taken seriously.<sup>34, 60</sup>

The transition process should involve a link paediatrician, a link adult cardiologist and a local congenital cardiac nurse. Local and national services should coordinate and carry out transition pathways concurrently. Clinically relevant information, records and care plan should be kept throughout the process.<sup>62</sup> 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/representatives

**8.2** NHS boards ensure that the transition process includes:

- the person with CHD and where appropriate their family/representatives
- a local congenital cardiac nurse
- an adult link cardiologist
- a link paediatrician
- specialist third sector organisations if requested.

- 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** A person-centred transition care plan is developed which is:
- led by the person and their representative
  - informed by the person's needs and desired outcomes
  - reviewed as needs change.
- 8.5** People with CHD are involved in discussions about who their transition plan is shared with and when.
- 8.6** People with CHD and where appropriate their family/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 changing circumstances during transition.
- 8.8** 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.
- 8.9** A person-centred plan for unscheduled care is in place during transition.

### What does the standard mean for young 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.

### What does the standard mean for staff?

Staff:

- plan transition between paediatric and adult services with input from relevant specialties
- listen to and involve people and, where appropriate, their families/representatives
- are able to signpost people and refer to support services appropriate to their needs.

### What does the standard mean for the NHS board?

NHS boards:

- follow a documented transition process for young people with CHD
- demonstrate close working relationships between local and national paediatric and adult services
- ensure that staff are supported to provide the right care, support and signposting to people with CHD during transition.

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

- Documented transition process.
- Individual and accessible transition plans.
- Young people's involvement in the design of transition processes and information resources.
- Support and peer groups for children, young people and their families/representatives.

# Standard 9: Preconception and pregnancy care

## Standard statement

Women/people with CHD who may become pregnant receive preconception care, counselling and specialist antenatal care.

## Rationale

Cardiovascular disease is the leading cause of perinatal death in the UK.<sup>47</sup> This risk can extend beyond the pregnancy.<sup>63</sup> Studies in women from Black and Asian ethnic backgrounds or from lower socioeconomic backgrounds show that they are at higher risk of maternal death, stillbirth and neonatal mortality.<sup>63, 64</sup>

Women/people with CHD who can become pregnant are more likely to have menstrual cycle disorders<sup>65</sup> which can result in infertility or miscarriage.<sup>66</sup> Support should be given to people with CHD exploring adoption or infertility treatment.

The World Health Organization has classified people's health risk during pregnancy. This classification (mWHO) can be used to support NHS boards to develop care pathways and manage risk.<sup>46</sup> Pregnant women/people in mWHO risk class II-III, III and IV, should be cared for by a multidisciplinary pregnancy heart team.<sup>47</sup> This includes a cardiologist, obstetrician and obstetric anaesthetist. It may also include specialists in genetics or sexual and reproductive health. Obstetric pathways should take account of local, regional, and national expertise and include access to a local congenital cardiac nurse.

Preconception care and counselling supports people to make informed choices about their future.<sup>67</sup> It can improve general pregnancy health and cardiovascular status. Pregnant women/people should be informed about their risk as soon as possible. Planning should consider anticoagulation, medication review, pain relief and anaesthetics.<sup>47</sup>

People 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/people with CHD who may become pregnant are routinely provided with:
- contraceptive advice and preconception care including advice to take folic acid
  - ongoing reassessment if medication is reduced or stopped.
- 9.2** Staff undertake a person-centred and validated risk assessment of women/people with CHD who may become pregnant, which considers:
- their cardiovascular status
  - co-morbidities
  - obstetric history
  - social factors that could impact outcomes for them and their baby.
- 9.3** NHS boards ensure that women/people 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.
- 9.4** Women/people who may become pregnant receive as indicated:
- information on the implications of anticoagulation during pregnancy for them and their baby, in partnership with a haematologist where relevant
  - a plan for anticoagulation, developed in partnership with a haematologist.

- 9.5** Women/people who may become pregnant have access to advice and information relating to all fertility and contraception 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.
- 9.6** Women/people who are pregnant are supported as early in pregnancy as possible to make informed choices, including, where appropriate, whether to continue a pregnancy.
- 9.7** Each NHS board has established referral and escalation pathways that include the national service for people with complex or high risk CHD requiring preconception counselling and pregnancy management.
- 9.8** Pregnant women/people with complex or high risk CHD, based on mWHO classification:
- are involved in the development of a joint obstetric and cardiology care plan which includes information on the frequency of assessment and review
  - have access to a multi-disciplinary team including CHD cardiologists, obstetricians and obstetric anaesthetists, relevant to their care plan
  - have access to echocardiography as required.
- 9.9** Pregnant women/people with CHD have an individual care plan which:
- is developed jointly with them and where appropriate their family/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 ensure staff:

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

**9.11** Following pregnancy, women/people with CHD have access to:

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

**What does the standard mean for people with CHD?**

- You will be fully informed about what may happen if you become pregnant to support you to make decisions about your future.
- You will be supported to make the right choice for you.
- Your risk in pregnancy will be assessed and shared with you.
- The team that looks after you when you are pregnant will be highly trained and specialist.
- You will be cared for and monitored throughout your pregnancy.

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

Staff:

- work in partnership to keep pregnant women/people with CHD safe
- provide advice and support to women/people with CHD who may become pregnant
- know who to go to for specialist advice and when to refer to the national service
- support people's choices about their future.

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

NHS boards:

- provide high quality local antenatal and postnatal support for pregnant women/people with CHD
- have protocols and referral pathways in place to ensure safe care for pregnant women/people with CHD
- share information, skills and expertise when needed.

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

- Assessment and documentation of risk in line with mWHO guidance.
- Evidence of multidisciplinary working as a pregnancy heart team, including team meetings and information sharing.
- Clinical audit and case review.
- Escalation and risk protocols.



# 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,<sup>68</sup> 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 services.
- 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 services 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
  - transport to the national services if required
  - 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/ people 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 services.
- 10.6** NHS boards have processes and referral pathways in place to facilitate safe, out of hours management of:
- people with heart rhythm emergencies
  - suspected failure of 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 developed in partnership with their specialist team
  - is shared with the person and held individually
  - 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/representatives are offered inclusive information in a format and language that is right for them about:
- their rights
  - the rights of their families/representatives
  - feedback and complaints procedures
  - who to talk to if they have any concerns about their health
  - 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 attendance in an emergency department 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 and taken seriously by healthcare professionals.
- You will receive accessible information about why you were in an emergency department and what might happen next.

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

Staff:

- have immediate access to future care plans
- receive immediate clinical information about people with CHD who attend an emergency department
- know when and how to access specialist support or advice, including from the national services.

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

NHS boards:

- have established pathways and procedures 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, personcentred health services. It is recognised under people's international right to health.<sup>69</sup> Palliative care improves the quality of life of people who are affected by life-threatening or life-limiting illness.<sup>70</sup> For people with particular congenital conditions, ongoing assessment and anticipatory care planning should be provided from an early age.<sup>71</sup> Meaningful conversations should take place with the person with CHD, and where appropriate their families/representatives, throughout their life. These conversations should take place in the context of the person's cultural or religious beliefs.<sup>72</sup> 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 families/representatives where appropriate
  - involve professionals with whom they have an ongoing relationship
  - are supportive, respectful and compassionate
  - meet their social, cultural and communication needs , including the use of signing or Easy Read information.
- 11.3** Families/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:
- perinatal bereavement support services
  - a local congenital cardiac nurse
  - specialist nursing teams such as heart failure specialist nursing
  - clinical or practitioner psychology teams
  - primary care
  - third sector support.
- 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
  - a designated lead or key contact for overseeing the review process and a key contact for families/representatives
  - notification to local cardiac services and other relevant services
  - access to the post mortem and written report of the post mortem
  - multidisciplinary learning and review processes as required.
- 11.7** In the instance of a child's death:
- families can access an independent key contact for information
  - families are provided with compassionate support
  - there is a joint child death review, including input from families/representatives
- 11.8** Each NHS board has established pathways for bereavement support for the families/representatives 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/representatives 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.



## 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](mailto: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/](http://www.healthcareimprovementscotland.org/)

## Appendix 2: Membership of the Standards Development Group

Name	Position	Organisation
Patrick Gibson (Co Chair)	Consultant Cardiologist	NHS Lothian
Patrick Noonan (Co Chair)	Consultant Paediatric Cardiologist	NHS Greater Glasgow and Clyde
Carla Benedetti	Cardiac Nurse Specialist Coordinator	NHS Greater Glasgow and Clyde
Susan Cassidy	Cardiac Clinical Psychologist	NHS Greater Glasgow and Clyde
Louise Chapman	Echo Physiologist, ACHD Services	NHS Grampian
Peter Currie	Consultant Cardiologist	NHS Tayside
Joanne Cusack	Cardiac Investigations Manager	NHS Greater Glasgow and Clyde
Adelle Dawson	Consultant Cardiologist	NHS Grampian
Frances Divers	Cardiology Nurse Consultant and Clinical Champion for Cardiac Rehabilitation	NHS Lothian and Scottish Government
Emma Finlay	Lead Physiologist	NHS Greater Glasgow and Clyde
Richard Forsyth	Health Systems Insight Manager - Scotland	British Heart Foundation
Rebecca Goldman	Consultant Paediatrician	NHS Tayside
Keir Greenhalgh	Consultant Paediatrician	NHS Lanarkshire
Karen Hogg	Consultant Cardiologist	NHS Greater Glasgow and Clyde
Deirdre Holly	Principal Clinical and Health Psychologist	NHS Golden Jubilee National Hospital
Jo Hughes	Head of Service Development	Down's Syndrome Scotland
Lindsey Hunter	Consultant Paediatric & Fetal Cardiology	NHS Greater Glasgow and Clyde

Name	Position	Organisation
Clare Irving	Consultant Paediatrician with special interest in CHD	NHS Borders
Vivien Jayne	Policy Officer	Down's Syndrome Scotland
Vera Lennie	Consultant Cardiologist	NHS Ayrshire & Arran
Stuart Lilley	Head of Paediatric Cardiac Physiology	NHS Greater Glasgow and Clyde
Roseanne McDonald	Associate Director for Specialist Services and National Planning	NHS National Services Scotland - National Services Division
Joelle Miller	SACHD Secretary	Chest Heart and Stroke
Mel Miller	Programme Manager	National Services Division
Lynn Miller	Consultant Cardiologist	NHS Fife
Marion Morris	Senior Policy Manager	Scottish Government
Liza Morton	Counselling Psychologist and person with lived experience of CHD	Somerville Foundation
Elaine Muirhead	Senior Specialist Nurse	NHS Golden Jubilee National Hospital
Lesley O'Brien	Cardiac Rehabilitation Physiotherapist	NHS Lanarkshire
Ruth Pegler	Clinical Psychologist	NHS Greater Glasgow and Clyde
Lindsey Pope	GP and Professor of Medicine	University of Glasgow
Jane Ramsay	Consultant Obstetrician	NHS Ayrshire & Arran
Jennifer Scotland	Consultant Paediatrician	NHS Tayside
Maggie Simpson	CHD Advance Nurse Practitioner	Scottish Obstetric Cardiac Network
Niki Walker	Consultant Cardiologist, clinical lead for Scottish Adult Congenital Cardiac Service	NHS Golden Jubilee National Hospital
Helen Zollinger	Parent of child with CHD	N/A

# References

1. NHS. Congenital Heart Disease. 2021 [cited 2023 Nov 01]; Available from: <https://www.nhs.uk/conditions/congenital-heart-disease/#:~:text=Congenital%20heart%20disease%20is%20a,babies%20born%20in%20the%20UK.>
2. Scottish Government. Heart disease: action plan. 2021 [cited 2023 Nov 01]; Available from: <https://www.gov.scot/publications/heart-disease-action-plan/>.
3. Morton L. Using psychologically informed care to improve mental health and wellbeing for people living with a heart condition from birth: A statement paper. *Journal of health psychology*. 2020;25(2)(2). Epub 20190207. 10.1177/1359105319826354
4. The Scottish Parliament. PE01446: Scottish Standards for the Care of Adult Congenital Heart Patients. 2012 [cited 2023 Nov 01]; Available from: <https://archive2021.parliament.scot/gettinginvolved/Petitions/AdultCongenitalHeartScottishStandards>.
5. NHS Golden Jubilee. Scottish Adult Congenital Cardiac Strategy 2022 to 2025 2022 [cited 2023 Nov 01]; Available from: [https://www.nhsgoldenjubilee.co.uk/application/files/3216/5910/7679/7.3\\_SACCS\\_Strategy\\_2022-25.pdf](https://www.nhsgoldenjubilee.co.uk/application/files/3216/5910/7679/7.3_SACCS_Strategy_2022-25.pdf).
6. United Nations. International Covenant on Economic, Social and Cultural Rights. 1966 [cited 2023 Nov 01]; Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>.
7. UNICEF. A summary of the UN Convention on the Rights of the Child. 2019 [cited 2023 Nov 01]; Available from: [https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC\\_summary-1\\_1.pdf](https://www.unicef.org.uk/wp-content/uploads/2019/10/UNCRC_summary-1_1.pdf).
8. United Nations. Convention on the Elimination of All Forms of Discrimination against Women New York, 18 December 1979. 1979 [cited 2023 Nov 01]; Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-elimination-all-forms-discrimination-against-women>.
9. Equality and Human Rights Commission. The United Nations Convention on the Rights of Persons with Disabilities: what does it mean for you? 2017 [cited 2023 Nov 01]; Available from: <https://www.equalityhumanrights.com/en/publication-download/united-nations-convention-rights-persons-disabilities-what-does-it-mean-you>.
10. United Nations. General comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights). 2016 [cited 2023 Nov 01]; Available from: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmIBEDzFEovLCuW1a0Szab0oXTdImnsJZZVQfQejF41Tob4CvljeTiAP6sGFQktiae1vlbbOAekmaOwDOWsUe7N8TLm%2BP3HJPzxiHySkUoHMavD%2Fpyfcp3YlZg>.
11. NHS England. Congenital Heart Disease Standards & Specifications. 2016 [cited 2023 Nov 01]; Available from: <https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf>.

12. NHSScotland. Local Services Paediatric and Adult Congenital Heart Disease Standards for NHS Scotland. 2018.
13. Healthcare Improvement Scotland. Learning from adverse events through reporting and review: A national framework for Scotland: December 2019. 2019 [cited 2023 Nov 01]; Available from: [http://www.healthcareimprovementscotland.org/our\\_work/governance\\_and\\_assurance/learning\\_from\\_adverse\\_events/national\\_framework.aspx](http://www.healthcareimprovementscotland.org/our_work/governance_and_assurance/learning_from_adverse_events/national_framework.aspx).
14. Scottish Government. Clinical and care governance framework: guidance. 2015 [cited 2023 Nov 01]; Available from: <https://www.gov.scot/publications/clinical-care-governance-framework/>.
15. Scottish Government. Health and Social Care Standards: my support, my life. 2017.
16. Independent National Whistleblowing Officer. National Whistleblowing Standards. 2021 [cited 2023 Nov 01]; Available from: <https://inwo.spsso.org.uk/national-whistleblowing-standards>.
17. BACPR. The BACPR Standards and Core Components for Cardiovascular Disease Prevention and Rehabilitation 2023. 2023 [cited 2023 Nov 01]; Available from: [https://www.bacpr.org/\\_data/assets/pdf\\_file/0021/64236/BACPR-Standards-and-Core-Components-2023.pdf](https://www.bacpr.org/_data/assets/pdf_file/0021/64236/BACPR-Standards-and-Core-Components-2023.pdf).
18. NHSScotland. The Charter of Patient Rights and Responsibilities. 2019.
19. Scottish Government. Person-centred care: advice for non-executive board members. 2019 [cited 2023 Nov 01]; Available from: <https://www.gov.scot/publications/person-centred-care-non-executive-members/pages/5/>.
20. NHS Education for Scotland. National Trauma Training Programme. 2022.
21. Realistic Medicine. Shared Decision Making. 2023 [cited 2023 Nov 01]; Available from: <https://realisticmedicine.scot/about/shared-decision-making/>.
22. Baumgartner H, De Backer J, Babu-Narayan SV, Budts W, Chessa M, Diller GP, *et al*. 2020 ESC Guidelines for the management of adult congenital heart disease. *Eur Heart J*. 2021;42(6):563-645. Epub 2020/08/30. 10.1093/eurheartj/ehaa554
23. Livecchi T, Morton L. *Healing Hearts and Minds*: Oxford University Press; 2023.
24. Cocomello L, Taylor K, Caputo M, Cornish RP, Lawlor DA. Health and Well-Being in Surviving Congenital Heart Disease Patients: An Umbrella Review With Synthesis of Best Evidence. *Frontiers in Cardiovascular Medicine*. 2022;9
25. Morton L. Using psychologically informed care to improve mental health and wellbeing for people living with a heart condition from birth: A statement paper. *Journal of health psychology*. 2020;25(2)(2):197-206. Epub 20190207. 10.1177/1359105319826354
26. NHS Education for Scotland. The Scottish Psychological Trauma Training Plan. 2019 [cited 2023 Nov 01]; Available from: <https://transformingpsychologicaltrauma.scot/media/5lvh0lsu/trauma-training-plan-final.pdf>.
27. Brida M, Simkova I, Jovovic L, Prokselj K, Antonova P, Balint HO, *et al*. European Society of Cardiology Working Group on Adult Congenital Heart Disease and Study Group for Adult Congenital Heart Care in Central and South Eastern

- European Countries consensus paper: current status, provision gaps and investment required. *European Journal of Heart Failure*. 2021;23(3):445-53.
28. Moons P, Bulck LV, Daelman B, Luyckx K. Mental health in adult congenital heart disease. *Internal Journal of Cardiology Congenital Heart Disease* 2023.
29. Kovacs AH, Brouillette J, Ibeziako P, Jackson JL, Kasparian NA, Kim YY, *et al*. Psychological Outcomes and Interventions for Individuals With Congenital Heart Disease: A Scientific Statement From the American Heart Association. 2022.
30. Gu S, Zhang Q, Katyal A, Chung W, Franciosi S, Sanatani S. Congenital Heart Disease and Autism Spectrum Disorders: Is There a Link? *Paediatrics and Child Health (Canada)*. 2022;27 Suppl 3:e4.
31. Stegeman R, Lamur KD, van den Hoogen A, Breur JMPJ, Groenendaal F, Jansen NJG, *et al*. Neuroprotective drugs in infants with severe congenital heart disease: A systematic review. *Frontiers in Neurology*. 2018;9(JUL):521.  
<https://dx.doi.org/10.3389/fneur.2018.00521>
32. Centers for Disease Control and Prevention. Adverse Childhood Experiences (ACEs): Preventing early trauma to improve adult health. 2021 [cited 2023 Nov 01]; Available from:  
<https://www.cdc.gov/vitalsigns/aces/index.html#:~:text=ACEs%20can%20include%20violence%2C%20abuse,and%20substance%20misuse%20in%20adulthood>.
33. Public Health Scotland. Adverse Childhood Experiences (ACEs). 2021 [cited 2023 Nov 01]; Available from: <https://www.healthscotland.scot/population-groups/children/adverse-childhood-experiences-aces/overview-of-aces>.
34. Chong LSH, Fitzgerald DA, Craig JC, Manera KE, Hanson CS, Celermajer D, *et al*. Children's experiences of congenital heart disease: a systematic review of qualitative studies. *European journal of pediatrics*. 2018;177(3):319-36.  
<https://dx.doi.org/10.1007/s00431-017-3081-y>
35. Cobham VE, Hickling A, Kimball H, Thomas HJ, Scott JG, Middeldorp CM. Systematic Review: Anxiety in Children and Adolescents With Chronic Medical Conditions. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2019;29.
36. Abda A, Bolduc ME, Tsimicalis A, Rennick J, Vatcher D, Brossard-Racine M. Psychosocial Outcomes of Children and Adolescents With Severe Congenital Heart Defect: A Systematic Review and Meta-Analysis. *Journal of Pediatric Psychology*. 2019;44(4):463-77.
37. Chin T, Horton H, Eagleson K, Kleinmahon J, Bora S. 679 Psychological Outcomes of Parents of Children With Congenital Heart Disease: A Systematic Review and Meta-Analysis. *Heart Lung and Circulation*. 2020;29 Suppl 2:S342.
38. Eagleson K, McCombs D, Kasparian N, Justo R, Bora S. Congenital Heart Disease and Families: A Systematic Review of Measures of Impact and Adaptation. *Heart Lung and Circulation*. 2019;28 Suppl 4:S347.
39. Kovacs AH, Bendell KL, Colman J, Harrison JL, Oechslin E, Silversides C. Adults with Congenital Heart Disease: Psychological Needs and Treatment Preferences. *Congenital Heart Disease*. 2009;4(3):139-46. 10.1111/j.1747-0803.2009.00280.x
40. COSLA, NHS Education for Scotland, Scottish Government, Improvement Service. Quality Indicators Framework for Trauma-Informed Services, Systems and Workforces Proposal and Development Plan: Stakeholder Consultation. [cited 2023 Nov 01]; Available from:

[https://www.improvementservice.org.uk/\\_data/assets/pdf\\_file/0025/29437/Trauma-Informed-Practice-Quality-Indicators-Framework-Consultation-v2.pdf](https://www.improvementservice.org.uk/_data/assets/pdf_file/0025/29437/Trauma-Informed-Practice-Quality-Indicators-Framework-Consultation-v2.pdf).

41. Huo Y, Couzner L, Windsor T, Laver K, Dissanayaka NN, Cations M. Barriers and enablers for the implementation of trauma-informed care in healthcare settings: a systematic review. *Implementation Science Communications*. 2023;4(1):49. 10.1186/s43058-023-00428-0
42. Scottish Government Mental Health Directorate. Delivery of psychological therapies and interventions: national specification. 2022 [cited 2023 Nov 01]; Available from: <https://www.gov.scot/publications/delivery-psychological-therapies-interventions-national-specification/pages/2/>.
43. Bliss for babies born premature or sick. Parents aren't visitors. 2023 [cited 2023 Nov 01]; Available from: <https://www.bliss.org.uk/research-campaigns/our-campaigns/parents-arent-visitors-take-action-to-keep-families-together>.
44. Yi-Fei Li K-YZ, Jie Fang, Chuan Wang, Yi-Min Hua, De-Zhi Mu. Efficacy of prenatal diagnosis of major congenital heart disease on perinatal management and perioperative mortality: a meta-analysis. *World Journal of Pediatrics*. 2016;12:298-307.
45. Xiuqing Qiu ZW, Min Liu, Xiujuan Chen, Qiumei Wu, Wen Ling, Hong Ma, Hailong Huang & Yuan Lin. Prenatal diagnosis and pregnancy outcomes of 1492 fetuses with congenital heart disease: role of multidisciplinary-joint consultation in prenatal diagnosis. *Scientific reports*. 2020;10.
46. Regitz-Zagrosek V, Roos-Hesselink JW, Bauersachs J, Blomström-Lundqvist C, Cifková R, De Bonis M, *et al*. 2018 ESC Guidelines for the management of cardiovascular diseases during pregnancy. *European Heart Journal*. 2018;39(34):3165-241. 10.1093/eurheartj/ehy340
47. Chattopadhyay R, Olwell B, Bhagra CJ. Maternal cardiac disease in pregnancy. *Obstetrics, Gynaecology and Reproductive Medicine*. 2022;32(1):1-7.
48. Healthcare Improvement Scotland. Pregnancy and Newborn Screening Standards. 2019 [cited 2023 Nov 01]; Available from: <https://www.healthcareimprovementscotland.org/our-work/standards-and-guidelines/stnds/pregnancy-screening-standards.aspx>.
49. Higgins C, Agarwal U, Ramaraj R, Lim JSL. Early Fetal Cardiac Screening: Detection of Congenital Heart Disease. *Cardiology in the Young*. 2022;32 Suppl 1:S83.
50. Public Health England. NHS Fetal Anomaly Screening Programme Congenital heart disease (CHD): information for parents. 2019 [cited 2019 Jun 11]; Available from: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/775164/Congenital\\_heart\\_disease\\_information\\_for\\_parents.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/775164/Congenital_heart_disease_information_for_parents.pdf).
51. British Congenital Cardiac Association Fetal Cardiology Standards Working Group. BCCA Fetal Cardiology Standards 2012.
52. Wieland ML, Szostek JH, Wingo MT, Post JA, Mauck KF. Update in Outpatient General Internal Medicine: Practice-Changing Evidence Published in 2017. *American Journal of Medicine*. 2018;131(8):896-901. <http://dx.doi.org/10.1016/j.amjmed.2018.01.046>
53. Scottish Government Digital Health and Care Directorate. Digital health and care strategy. 2021.



54. Maggie Simpson, Emma Weingart, Jane Lewis, Toni Hardiman, Antonia Docherty, David Rogers, *et al.* The role of the nurse in adult congenital heart disease: past, present and future. *British Journal of Cardiac Nursing*. 2022.
55. Beningfield A, Jones A. Peri-operative chest physiotherapy for paediatric cardiac patients: a systematic review and meta-analysis. *Physiotherapy*. 2018;104(3):251-63. <https://dx.doi.org/10.1016/j.physio.2017.08.011>
56. Capone GT, Chicoine B, Bulova P, Stephens M, Hart S, Crissman B, *et al.* Co-occurring medical conditions in adults with Down syndrome: A systematic review toward the development of health care guidelines. *American Journal of Medical Genetics, Part A*. 2018;176(1):116-33. <http://dx.doi.org/10.1002/ajmg.a.38512>
57. Kawata M, Ohuchi H, Akagi T, Ichikawa H, Inai K, Kasahara S, *et al.* JCS 2022 Guideline on Management and Re-Interventional Therapy in Patients With Congenital Heart Disease Long-Term After Initial Repair. *Circulation Journal*. 2022;86(10):1591-690.
58. Singal A, Sahu MK, Trilok Kumar G, Kumar A. Effect of energy- and/or protein-dense enteral feeding on postoperative outcomes of infant surgical patients with congenital cardiac disease: A systematic review and meta-analysis. *Nutrition in Clinical Practice*. 2022;37(3):555-66.
59. TIER. Ready Steady Go Programme. 2022 [cited 2023 Nov 01]; Available from: <https://www.readysteadygo.net/rsg.html>.
60. Constantine A, Tulloh RMR, Turquet R, Dimopoulos K, Moledina S. PAH-CHD: transition to adulthood. *Journal of Congenital Cardiology*. 2020;4 Suppl 1.
61. Ricci P, Dimopoulos K, Bouchard M, Zhiya CC, Meira VC, Pool D, *et al.* Transition to adult care of young people with congenital heart disease: impact of a service on knowledge and self-care skills, and correlates of a successful transition. *European heart journal Quality of care & clinical outcomes*. 2023;15.
62. Bollegala N, Kailas T, Marani H, Tabatabavakili S. A Systematic Review on Models of Care in Pediatric to Adult Transition of Care. *Journal of the Canadian Association of Gastroenterology*. 2019;2(Supplement 2):258-9.
63. MBRRACE-UK. Saving Lives, Improving Mothers' Care. 2022.
64. MBRRACE UK. MBRRACE-UK Perinatal Mortality Surveillance Report UK Perinatal Deaths for Births from January to December 2019. 2021 [cited 2023 Nov 01]; Available from: [https://www.npeu.ox.ac.uk/assets/downloads/mbrance-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK\\_Perinatal\\_Surveillance\\_Report\\_2019\\_-\\_Final\\_v2.pdf](https://www.npeu.ox.ac.uk/assets/downloads/mbrance-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf).
65. Joy E, Skorupskaite K, Balen A, Cauldwell M, Agarwal K, English K. Outcomes of fertility treatment in patients with cardiac disease: A multi-centre experience. *European Heart Journal*. 2021;42 Suppl 1:2897.
66. Garcia Ropero A, Baskar S, Roos Hesselink JW, Girnius A, Zentner D, Swan L, *et al.* Pregnancy in Women With a Fontan Circulation: A Systematic Review of the Literature. *Circulation Cardiovascular Quality & Outcomes*. 2018;11(5):e004575.
67. Scottish Obstetrics Cardiology Network. Pre Conception Counselling. 2023 [cited 2023 Nov 01]; Available from: <https://www.socn.scot.nhs.uk/professionals/pre-conception-counselling/>.
68. Diddle JW, Riley CM, Hom LA, Klugman D. Open Hearts: Sharing Data to Improve Outcomes in Congenital Heart Disease. *Current Treatment Options in Pediatrics*. 2020;6(4):263-73.



69. World Health Organization. Palliative care. 2020 [cited 2023 Nov 01]; Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
70. NHSScotland. Scottish Palliative Care Guidelines. 2022 [cited 2023 Nov 01]; Available from: <https://www.palliativecareguidelines.scot.nhs.uk/>.
71. Schwerzmann M, Goossens E, Gallego P, Kovacs AH, Moons P, Swan L, *et al*. European Heart Journal - Recommendations for advance care planning in adults with congenital heart disease. 2020.
72. Millerick Y. Supportive Palliative Care in Heart Failure Pumping Marvellous Foundation; 2022.



Healthcare  
Improvement  
Scotland

**Evidence**  
Advice, guidance  
and intelligence

You can read and download this document from our website.  
We are happy to consider requests for other languages or formats.  
Please contact our Equality and Diversity Advisor on 0141 225 6999  
or email [contactpublicinvolvement.his@nhs.scot](mailto:contactpublicinvolvement.his@nhs.scot)

Healthcare Improvement Scotland

Edinburgh Office  
Gyle Square  
1 South Gyle Crescent  
Edinburgh  
EH12 9EB  
0131 623 4300

Glasgow Office  
Delta House  
50 West Nile Street  
Glasgow  
G1 2NP  
0141 225 6999

[www.healthcareimprovementscotland.org](http://www.healthcareimprovementscotland.org)