

NATIONAL CARDIAC AUDIT PROGRAMME

# ANNUAL REPORT FOR PATIENTS AND THE PUBLIC

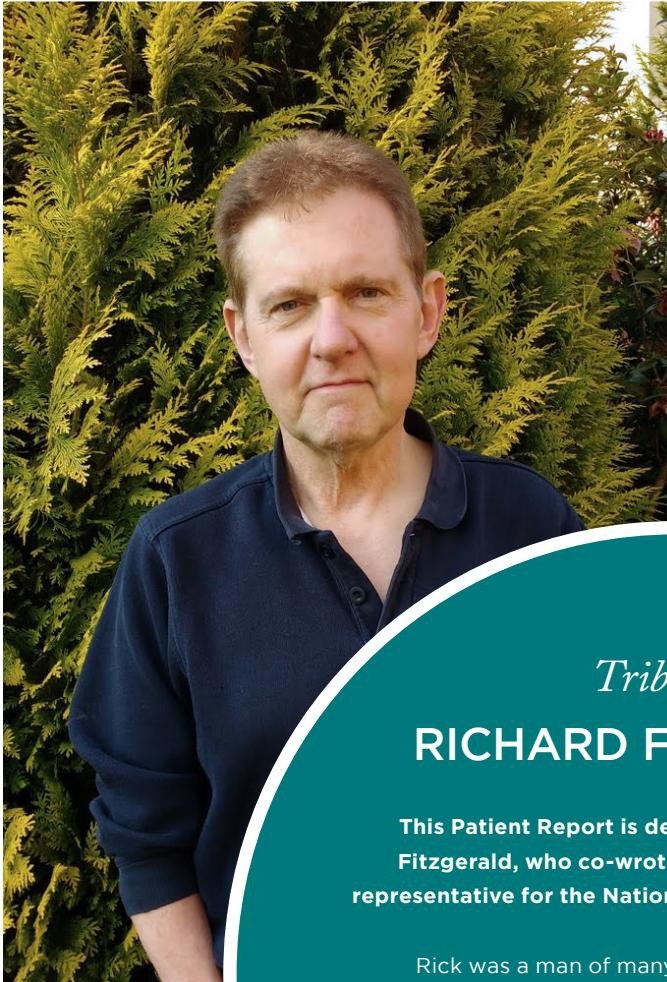
SEPTEMBER 2019



**NICOR**

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*Tribute to*  
**RICHARD FITZGERALD**

**This Patient Report is dedicated to Richard (Rick) Fitzgerald, who co-wrote it and acted as a patient representative for the National Cardiac Audit Programme.**

Rick was a man of many talents. He was a gifted musician and singer and a formidable legal opponent in the courtroom in his long career as a solicitor. He was passionate about improving outcomes for patients and dedicated his time to representing the patient perspective in many cardiovascular projects, programmes and services. Rick played a key role for Cardiovascular Care Partnership and other organisations and societies. He passed away following a cardiac arrest and will be sadly missed.





# ABOUT THIS REPORT

This patient report is designed as a companion to the **2019 National Cardiac Audit Programme (NCAP)** report produced by the **National Institute for Cardiovascular Outcomes Research (NICOR)**, which has been carrying out national cardiac audits on behalf of the Healthcare Quality Improvement Partnership (HQIP) since 2011. NICOR is hosted by Barts Health NHS Trust.

The primary aim of NCAP is to support and drive quality improvement within hospitals. For this reason our annual report is aimed at those with some level of clinical knowledge. This patient report is intended to be accessible to all patients, family members, carers and members of the public.

You can download the 2019 NCAP annual report at <https://www.nicor.org.uk/national-cardiac-audit-programme/>, covering data from the 2017/18 financial year. For some of the measures, three years' data are considered (i.e. 2015/16 - 2017/18). The 2019 NCAP annual report covers three main quality improvement themes. These are:

- ▶ **Timely care** (how long it takes for patients to get treatment)
- ▶ **Specialist care** (whether patients are seen and treated by people who have experience of their specific condition and in the best clinical environment for that condition)
- ▶ **Evidence based and equitable care** (whether national recommendations for healthcare based on scientific research are being met, and whether there are likely to be differences in the quality of care for patients depending on where they live). The main findings and recommendations from the report are available online as "[key messages](#)"





# HOW TO USE THIS REPORT

The report is divided into the six areas of clinical expertise (called “specialties”) audited by NCAP. We have summarised some of the key findings from the full 2019 annual report, provided useful background information and highlighted what you can do to help improve cardiac health for you and your friends and family. We’ve also included answers to some frequently asked questions and links to where to go for more information or support. If you would like to read specific parts of the annual report the relevant page numbers are provided so that you can view the report data.

## WHY DO WE AUDIT?

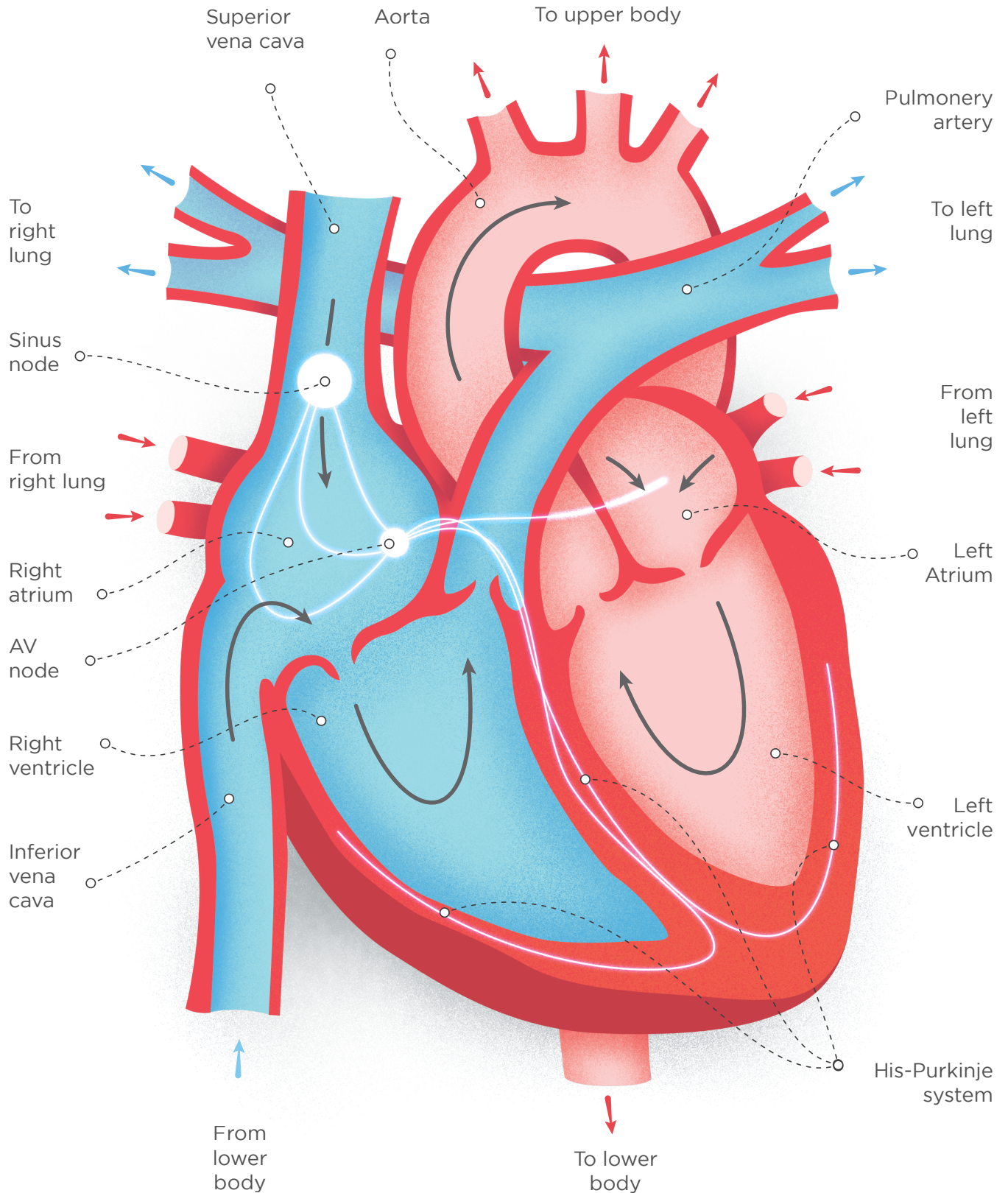


The NHS has been carrying out regular national clinical audits since the 1980s. The practice of clinical audit is much older. Florence Nightingale meticulously recorded both death rates and the causes of death in the Crimea which led to the introduction of better hygiene practices and improvements in living conditions, saving lives.

The information routinely collected from clinical audit is key to public health research. Many discoveries which have improved millions of lives worldwide have been made by analysing patient data, or the patient data have highlighted important areas of clinical research for medical researchers. For instance, the links between smoking and obesity and heart disease (among other important factors) were discovered in a study of 35,000 British doctors which ran for 50 years.

The audit work we carry out at NICOR helps the National Health Service (NHS) to define the standards used for evidence-based cardiac healthcare and monitors that those standards are being met. It recommends actions which can help hospitals and medical professionals improve, and also enables large healthcare organisations and commissioners to look at the national picture. It also provides data to help further research, the findings of which may then become very important for the audit programme.

# AN INTRODUCTION TO YOUR HEART



Before we explore the different areas of cardiac healthcare or “specialties” let’s take a brief look at how the heart works, which will help us understand how things can sometimes go wrong.

Your heart is amazing. It is the central point of your circulatory system.

The heart is a muscle made of four chambers which pumps blood and oxygen constantly, supplying your whole body, and responding to extra demand placed on it, such as vigorous exercise, when needed. The rhythm of your heartbeat is regulated by electrical signals from the heart’s “natural pacemaker”, the **sinus node** in the **right atrium**, which make your heart muscle contract and relax at a steady pace to pump the blood.

If either of these systems fails to work properly, it will cause health problems. If the arteries which channel blood to your heart muscle become blocked either partially or fully you can experience a **heart attack**. The treatment for this includes drug therapy, **percutaneous coronary intervention (PCI)** (a procedure using a balloon and stent(s) to open up an artery) or **cardiac surgery**. Or if the electrical system is not working properly the rhythm of the heart might be irregular, too fast, too slow, or the heart can even suddenly stop beating altogether, which is a **cardiac arrest** (see fact box on page 16). Both of these cardiac events are medical emergencies and the person must receive treatment fast to maximise the chances of survival.

**Heart failure** is the term doctors use for when the heart is no longer able to pump the blood around the body as well as it should. This can be for a variety of reasons, such as disease of the heart muscle (known as cardiomyopathy) or the long-term damaging effects of high blood pressure, but commonly it occurs after a heart attack when the heart muscle can be permanently damaged.

Cardiac **arrhythmia** is an abnormal heart rhythm. A relatively common form of arrhythmia is **atrial fibrillation** (see fact box on page 15). This can lead to abnormal flow in the heart chambers, and sometimes results in a clot forming in a heart chamber. If this breaks off into the circulation it can cause a stroke. A number of implantable devices such as **pacemakers** and **defibrillators**, and treatments such as **ablation** can be used to regulate heart rhythm.

Finally babies can be born with structural problems of the heart. These abnormalities are called **congenital heart disease**, and urgent surgery may be required on the baby’s heart before the first birthday, often within the first couple of weeks after birth. Many of these heart problems are discovered through routine antenatal screening offered to pregnant women at 20 weeks of pregnancy or earlier. Where this is possible, it enables doctors to plan treatment of these babies before their mothers give birth, helping to improve their survival rate. However some more minor congenital heart conditions are not detected before birth as they are not easily seen on the scan.



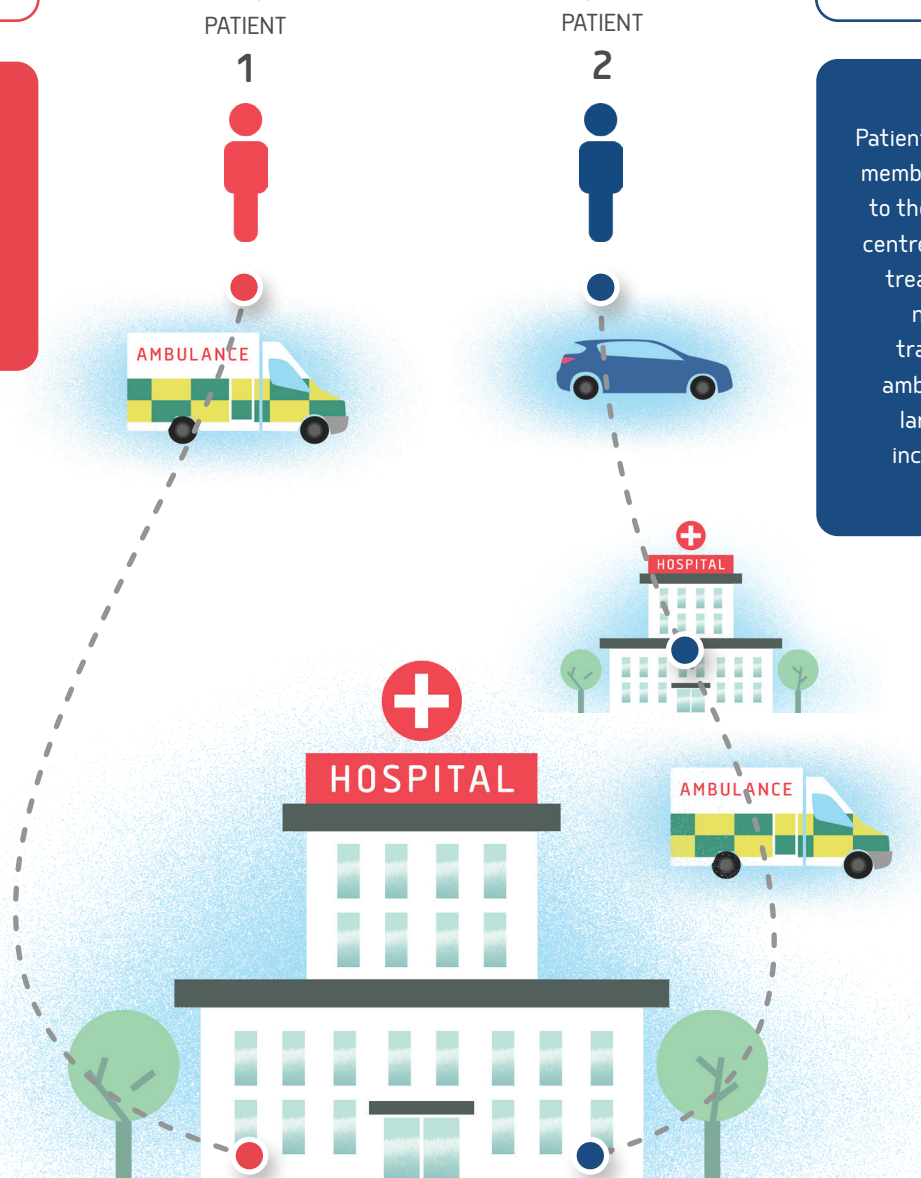
An average\* of **122** minutes from call to treatment

Patient 1 calls an ambulance and is taken directly to a large hospital with an heart attack centre.

Two patients with heart attack symptoms in the same town...

An average\* of **153** minutes from call to treatment

Patient 2 asks a family member to take them to the nearest small centre and cannot be treated there, so needs to be transferred by ambulance to the large hospital, incurring delay.



## A HEART ATTACK IS A MEDICAL EMERGENCY

Call 999 urgently for an ambulance which will take you to the best available treatment centre. Do not attempt to take yourself to hospital. Fast treatment could save your life.

## HEART ATTACK SYMPTOMS

- ⚡ Sudden pain, pressure or discomfort in your chest that doesn't go away.
- ⚡ The pain may radiate to one or both arms or your neck, jaw, back or stomach.
- ⚡ This can be severe for some people, and others simply experience discomfort.
- ⚡ You may also start to sweat, feel sick, breathless, faint, dizzy, or a sense of panic.

It's possible to have a heart attack without experiencing sudden chest pain - this is more common in women and people with certain conditions which affect how pain is experienced.

You can read more about heart attack symptoms [here](#).

\* Based in each case on the median time, i.e. the time in minutes from calling for help to receiving treatment, when 50% of the specified group of patients will have received treatment at a hospital heart attack centre capable of treating them.



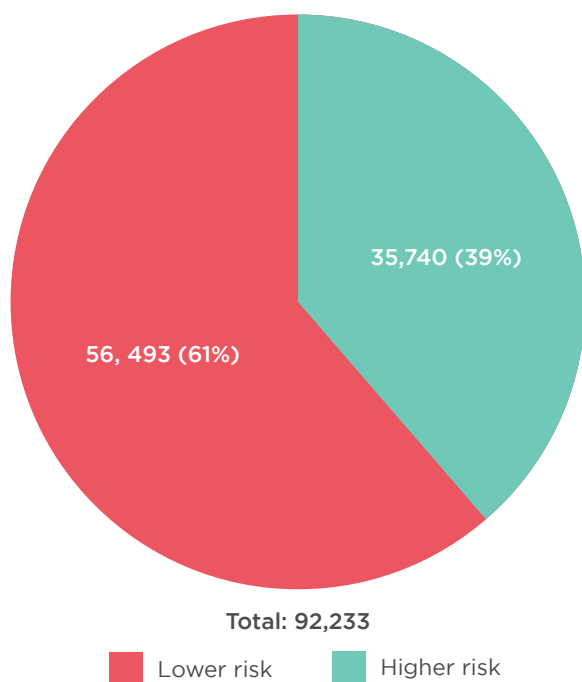
# HEART ATTACK (MYOCARDIAL INFARCTION)

With data from the Myocardial Ischaemia National Audit Project (MINAP)

## QUICK FACTS

- ▶ Men are more likely to have a heart attack at a younger age. Smokers are also more likely to have a heart attack younger than non-smokers.
- ▶ Body Mass Index (BMI) is also a factor. Compared with a BMI of 25, women with a BMI of 40 are about 10 years younger, and men 8 years younger, when they first have a heart attack.
- ▶ There was a prior diagnosis of diabetes in 21.1% of heart attack patients, with 20.5% of men and 22.4% of women having the condition.

Number of heart attacks in 2017/18 by lower/higher risk type



As explained in the introduction, most heart attacks happen when a coronary artery becomes blocked either partially or fully. This condition is known as **acute coronary syndrome**. If the blood flow is fully blocked, a particular change is usually seen with a test called an **electrocardiogram (ECG)**, which is carried out immediately on admission to hospital or ideally in the ambulance by paramedics. This is the highest risk type of heart attack (called a “STEMI” by doctors after the specific pattern it makes on the ECG) and is an emergency situation (see the infographic on the

previous page) requiring urgent unblocking of the artery. The symptoms felt during a heart attack occur because damage is being caused to the heart by the reduced blood supply. Doctors use the ECG and some other tests (see below) to assess whether someone has had a heart attack. Delays accessing treatment can reduce the chances of surviving the attack, and increase the chances of further permanent damage to the heart or serious complications.

There is another more common type of heart attack which is less immediately life-threatening, but can lead to serious health problems later on. This is when a coronary artery has narrowed to the point where blood cannot easily pass through. Often the heart will have developed its own protective action to minimise potential damage, but the heart is vulnerable. Sometimes a clot develops in the artery, partly blocking the channel and causing a heart attack. When an ECG is carried out, the pattern is different from the higher risk heart attack, and doctors call it an “NSTEMI”.

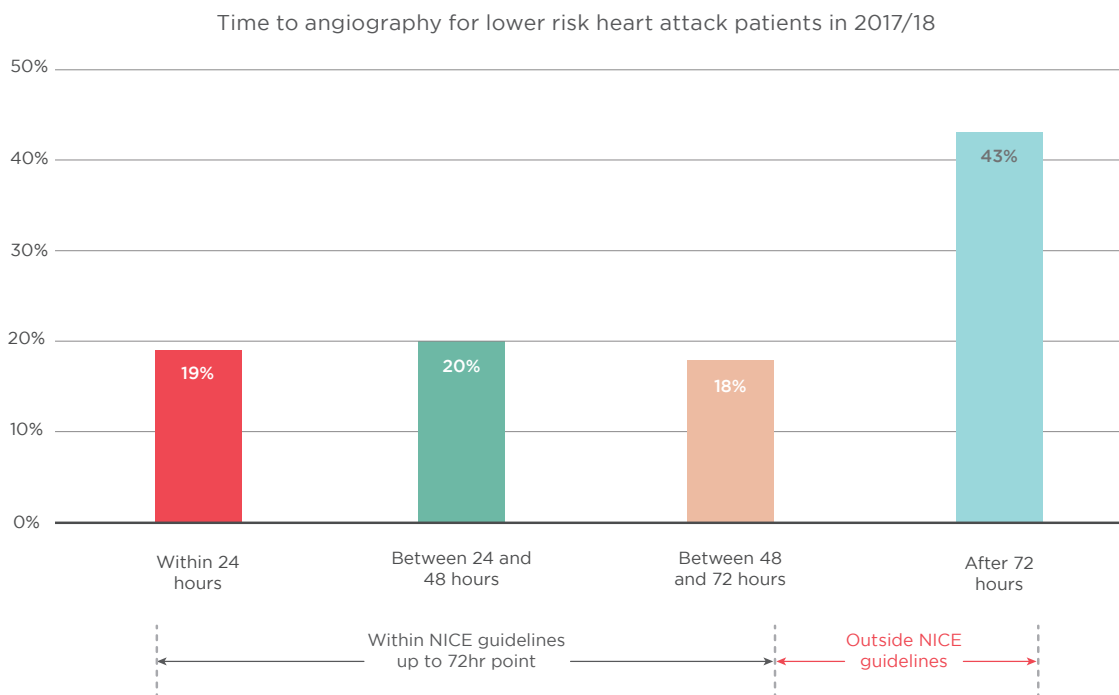
Other tests which can help to diagnose a lower risk heart attack include a **troponin** test, which measures levels of a chemical released into your blood when your heart muscle is damaged, or an **echocardiogram (echo)**. An **echocardiogram** is an ultrasound scan which bounces sound waves off different parts of your heart, and uses the echoes produced to create an accurate picture of your heart’s structure and blood flow on a screen.

**Angiography** is a procedure that uses X-rays to check the health of your blood vessels and how blood flows

through them. This is done by inserting a thin catheter into an artery and injecting a dye which highlights the blood flowing in your veins and arteries, and shows up any blockages and narrowings. It helps the consultant cardiologist decide which treatment is likely to be the best for you.

Sometimes this test, called an **angiogram**, is carried out immediately on arrival in hospital, as part of

emergency treatment in the case of a higher risk heart attack. For a higher risk heart attack the delay between admission to hospital and having an angiogram is measured in minutes. For a lower risk heart attack national guidelines (from the National Institute for Health and Care Excellence (NICE)) recommend that an angiogram is performed within 72 hours of admission.



Getting medical attention as early as possible in either case is critical, but particularly for the higher risk type of heart attack. Our infographic on page 6 demonstrates the need to call an ambulance if you think you may be having a heart attack.

National and international guidelines suggest that patients with a higher risk heart attack should receive treatment (usually a primary percutaneous coronary intervention (PCI) – see page 6) within 90 minutes of

arrival at a hospital with a heart attack centre. This is achieved for 88% of patients.

Half of all patients with higher risk heart attacks who call 999 will have received primary PCI in a hospital heart attack centre within 122 minutes. This rises to within 153 minutes when an inter-hospital transfer is needed, due to the patient first going to a hospital without the facilities or staff to carry out primary PCI, as the infographic on page 6 shows.

## USEFUL RESOURCES FOR HEART ATTACK PATIENTS:

- ▶ Heart UK (cholesterol charity) <https://www.heartuk.org.uk/>
- ▶ <https://www.nhs.uk/conditions/heart-attack/recovery/>
- ▶ <https://www.bhf.org.uk/information-support/conditions/heart-attack>

# PERCUTANEOUS CORONARY INTERVENTION (PCI)

With data from the National Audit of Percutaneous Coronary Interventions (PCI)

## QUICK FACTS

- ▶ Overall there were 102, 258 PCI procedures (for all indications) performed for patients in the UK in 2017/18. These were carried out in 118 PCI centres.
- ▶ PCI has become the preferred method to treat high risk heart attacks (“STEMI”) in the last 17 years. When PCI is used for this treatment it is known as “primary PCI”. In 2017/18 the number of primary PCIs carried out was 25,939, from virtually none in 2001.
- ▶ 58 of the 118 PCI centres are set up to perform these primary PCIs 24/7 every day of the year as an emergency treatment for high risk heart attacks.

If you experience a high risk heart attack, the preferred treatment in the UK is emergency or **primary PCI** (also known as **primary angioplasty**) to restore blood flow to the heart as soon as possible, to stop further damage. On the previous page, we saw how the heart attack diagnosis is made by performing an **ECG**. Another important reason for calling an ambulance (rather than taking yourself to your local hospital’s Accident & Emergency (A&E) department) is that if a heart attack is suspected, this test can often be carried out by paramedics at your home, so making sure that you are taken to the correct hospital (a heart attack centre – see below) which will be warned you are on the way, saves precious time so that you can undergo the most appropriate treatment as soon as possible.

As we saw in the infographic on page 6, the ambulance will normally take you to a hospital which is a heart attack centre where this procedure is performed regularly (which may not be your local hospital). This is because larger or specialised hospitals tend to have better facilities such as a 24-hour service, a dedicated treatment room (a “cath lab”), as well as a clinical team who are used to seeing heart attack patients and performing the angioplasty procedure as an emergency treatment.

If you present yourself at the nearest A&E with symptoms of a heart attack you will often have to wait longer for treatment, as the diagnosis will first need to be confirmed. If there are no available facilities on site, you will need to be transferred by ambulance to the nearest hospital which can perform the angioplasty,

causing unnecessary delay to you getting the treatment you need.

Once you arrive at the hospital cath lab, a fine tube, known as a catheter, is passed to your heart arteries under local anaesthetic to find out where the blockage is. Then a balloon and wire mesh “stent” will be used to open up the blockage and restore blood flow to your heart muscle. The catheter can be inserted from either a blood vessel in your groin (femoral artery) or your wrist (radial artery). The use of the wrist is associated with fewer complications, including reduced bleeding. As a result there has been a trend towards using this access in the last decade with **87.2%** of PCIs being carried out through the wrist rather than the groin in 2017/18. This will never be 100% because for some patients the groin is the best entry point. It’s estimated that **450 lives were saved** due to the use of the radial artery for angioplasty in the period 2005–2012.

Once a balloon has restored blood flow, a stent (a tiny scaffold which helps hold open the artery) is then put in place and will remain there. Other technological advances have been made, and most stents are now “drug eluting”, containing specific drugs which minimise the risk of the artery re-narrowing due to scar tissue growing around the stent as the artery heals.

## DAY CASE PCI - WHERE YOU DON'T NEED TO STAY IN HOSPITAL OVERNIGHT AFTER A NON-URGENT PROCEDURE

PCI techniques have improved so the procedure is generally less invasive and with less risk of complications than in the past, and it's often possible and safe to have the procedure and go home the same day. It will depend on your condition and where you have the procedure, as some hospitals still prefer to keep patients in overnight.

On a national level currently **63.6%** of elective PCI procedures are performed as day cases.

## PCI FOR PATIENTS WHO HAVE HAD A LOWER RISK HEART ATTACK

National and international guidelines recommend that patients within this category should receive PCI if suitable within 72 hours of admission to hospital. The percentage is improving, but currently the target is achieved for **54.8%** of patients.

## USEFUL RESOURCES FOR PCI PATIENTS:

- ▶ <https://www.bhf.org.uk/informationsupport/treatments/coronary-angioplasty-and-stents>
- ▶ <https://www.nhs.uk/conditions/coronary-angioplasty/>
- ▶ <https://www.bcis.org.uk/patient-area/>



# ADULT CARDIAC SURGERY

Data from the National Audit for Adult Cardiac Surgery

## QUICK FACTS

- ▶ The first coronary artery bypass graft operation was carried out in 1960.
- ▶ A total of 32,295 cardiac operations were performed in 2017/18.
- ▶ 14,527 first time, non-emergency coronary artery bypass graft (CABG) operations were carried out in 2017/18.
- ▶ On average, there was a 99% survival rate for patients having a non-emergency CABG in 2017-18 in the UK.
- ▶ 5,158 first time aortic valve replacement (AVR) operations were carried out in 2017/18, with a further 2766 carried out in combination with a coronary artery bypass graft operation (AVR + CABG).
- ▶ On average, there was a 99% survival rate for patients having a non-emergency AVR in 2017/18 in the UK.

Adult Cardiac Surgery includes all procedures performed on patients aged 18 or over that involve the heart or structures attached to the heart. For the purposes of the audit these operations involve opening the chest wall (via the breastbone or ribs) and usually the pericardium (the sac around the heart). Heart operations include Coronary Artery Bypass Grafts (CABG); valve replacement or repair; aortic surgery (surgery on the body's main artery); or a combination of these. Procedures on the heart not requiring the chest to be opened surgically and surgical procedures on babies and children are reported elsewhere in this report.

Coronary Artery Bypass Graft operations treat patients who have angina (chest pain) as a result of a narrowing or blockage in their coronary arteries. This involves taking a healthy artery or vein from elsewhere in the body and surgically joining (grafting) it to the affected coronary artery above and below the point of narrowing, allowing blood to flow around ("bypass") the blockage and reach the heart muscle without restriction.

**Coronary artery bypass grafting (CABG)** is occasionally performed as an emergency operation straight after the patient has been diagnosed with a heart attack. However, following most heart attacks it is more usually performed as an urgent in-patient surgery scheduled several days after the initial angiogram (see Heart Attack on page [7](#)). For patients with more stable symptoms of chest pain, the operation is usually performed on an elective basis,

where the patient is admitted from home for their operation in a planned fashion.

Generally at the time of a heart attack you will be given **anti-platelet drugs**, which thin your blood and reduce clotting to counter the effects of the narrowed or blocked artery. This often means that it could be more dangerous to operate during the first few days after stopping these drugs, due to the increased risks of bleeding with surgery. Consequently, there needs to be a waiting period before an operation (commonly 5 days, depending on which drugs have been used). Also, a cardiac surgery patient will need to be kept on an intensive care ward after the surgery which needs to be coordinated and planned with care.

On average in the UK, it takes **10 days** for a patient identified by angiography as having an urgent need for the coronary artery bypass grafting surgery to have the operation. National guidelines state that it should be carried out within 7 days. NICOR's [audit](#) has highlighted this shortfall so that quality improvement programmes can be put in place to address it on a national and local level.

The chance of dying is low for this complex operation. In 2017/18 (excluding emergency surgery which carries a higher risk) **99.01%** of people survived to be discharged home from hospital following their operation.

## POSSIBLE COMPLICATIONS OF CORONARY ARTERY BYPASS GRAFTING SURGERY

**Deep wound infection** - where the breastbone or tissues around the heart develop an infection. This is often life-threatening and can require extensive further treatment in intensive care and possible reconstructive surgery, delaying recovery. The rate in the UK is 0.3% of cases (2017/18).

**Reoperation due to bleeding** - during surgery, appropriate drugs are given to prevent blood clots forming while using the heart-lung machine (this pumps the blood around the body while a patient's heart is being operated on). At the end of the operation other drugs are given to enable the blood to clot again, so that healing can take place. However, in the first few hours after surgery further bleeding is a relatively common complication, which occasionally means that the patient needs to be operated on again (to identify and control the site of any bleeding). Patients that bleed after heart surgery often need

to receive a blood transfusion. Whilst a transfusion is usually safe, it is better to avoid if possible. The rate in the UK for reoperations for bleeding is 2.57% (2017/18).

**Stroke** - occasionally a patient will suffer a stroke following the operation. Sometimes the symptoms fully resolve within 24 hours (a "transient" stroke), but occasionally the stroke will be more permanent (and can be life-changing). In around half of "permanent" strokes the symptoms will still resolve, but take longer to do so, usually within several days or weeks. The stroke rate in the UK (for both transient and "permanent" strokes combined) is 0.61% (2017/18).

**Kidney failure** - around a quarter of blood pumped in every heartbeat passes through the kidneys. Kidney failure after surgery can either be due to an existing kidney problem or due to reduced heart function (leading to reduced blood flow to the kidneys). This may require treatment in the intensive care unit after the operation to filter the blood of toxins normally removed by the kidneys (using dialysis or haemofiltration). The rate of kidney failure after a coronary artery bypass graft operation in the UK is 1.63% (2017/18).

### USEFUL RESOURCES FOR ADULT CARDIAC SURGERY PATIENTS:

- ▶ <https://www.bhf.org.uk/informationsupport/treatments/coronary-bypass-surgery>
- ▶ <https://www.rcseng.ac.uk/patient-care/recovering-from-surgery/coronary-artery-bypass/>
- ▶ <https://www.nhs.uk/conditions/aortic-valve-replacement/what-happens/>



# HEART FAILURE

Data from the National Heart Failure Audit

## QUICK FACTS

- ▶ 68,266 patients presented at hospital with symptoms of heart failure between April 2017 and March 2018.
- ▶ 82% of patients were seen by heart failure specialists.
- ▶ 88% were given an echocardiogram and 86% an electrocardiogram (ECG) to look at their heart and assess its condition (see Heart Attack on page 7 for details of these tests).
- ▶ The average age of heart failure patients (men and women combined) is 80. As with other heart problems, men tend to be slightly younger when they are admitted to hospital for heart failure.
- ▶ The rate of UK heart failure patients who die in hospital is 10.1%. This is partly due to the older patients (over 75) who may have other medical conditions, and their rate is subsequently higher (12%). The rate for patients under 75 is 5.7%.
- ▶ After 1 year from discharge the survival rate of patients is 68%, but this can depend on a number of factors. Many patients with mild or moderate heart failure can survive many years if they are given the right treatment.

Heart failure (see also the description in the introduction on page 5) occurs for a number of reasons and is often a secondary effect of other heart problems such as: a heart attack, when the heart muscle is damaged; damage caused by the increased strain on the heart from high blood pressure; or cardiomyopathy, which is a disease of the heart muscle; as well as other causes. It essentially means that the heart is failing to pump as well as it should and can cause symptoms such as weakness, breathlessness, fatigue and swelling around the legs. It cannot be cured, but in many cases patients can manage their condition with drugs and other therapies.

Heart failure can be missed or confused for other conditions, even in hospital. Patients are sometimes treated on a general medical ward for the whole of their stay, even when their heart failure has been diagnosed.

Specialist care is important. Patients treated by specialists are more likely to receive key tests like ECGs and echocardiograms, which help cardiologists see the heart's reduced function and determine the best treatment, which might be surgery or an implantable device (see Arrhythmia/Cardiac Rhythm Management on page 15). They are also more likely to receive the appropriate triple-drug

therapy (see below), to be offered follow-up out-patient appointments and to be referred to a cardiac rehabilitation programme (see fact box below), which has been shown to help cardiac patients recover and lead as full a life as possible with their condition. All of these factors are associated with a higher rate of survival after one year.

## THE IMPORTANCE OF CARDIAC REHABILITATION

Cardiac rehabilitation (rehab) is a tailored medically supervised programme of exercise, support and advice to help you learn to manage your heart condition after a heart attack, diagnosis of heart failure, cardiac surgery or other procedure. Research has shown this can improve your life, boost your confidence and increase the likelihood of you making as full a recovery as possible. You should be referred to a cardiac rehab programme by the hospital where you are treated.

However, not all patients are referred to cardiac rehab. National guidelines recommend that patients admitted to hospital with heart failure, and those who have had cardiac surgery, should

be referred to a cardiac rehab programme before being discharged from hospital, and ideally should be encouraged to carry on the activities after the programme ends and incorporate them into their lives. However, for heart failure only 15.2% of patients were referred to a programme before they left hospital (although community teams may refer others, but this is not captured by the audit). You are significantly more likely to be referred if you were treated on a cardiology ward. You can find a list of programmes and more information here: <http://www.cardiacrehabilitation.org.uk/patient-information.htm>

## DRUG THERAPY FOR HEART FAILURE

There are three drugs recommended for heart failure. A patient not discharged on any of these drugs has a significantly lower chance of still being alive a year on from discharge from hospital for heart failure (52% for the most common form of heart failure) than a patient discharged on all three drugs (81%).

**The three drugs recommended for heart failure are:**

### ACE INHIBITORS/ARBs

These drugs (angiotensin-converting enzyme inhibitors/angiotensin receptor blockers) affect an enzyme (angiotensin-converting enzyme) in your blood which can narrow your blood vessels, increasing your blood pressure and making your heart work harder to pump blood around your body. Taking this drug can often ease this narrowing of the vessels and lower your blood pressure. Watch this video from the British Heart Foundation: <https://youtu.be/xllaQuRaZmk>.

### BETA BLOCKERS

Beta blockers block the action of the stress hormones adrenaline and noradrenaline which cause your heart to beat faster. This slows your heart rhythm and reduces the demand on your heart. Watch this video from the British Heart Foundation: <https://youtu.be/uiYJKvwVhEU>.

### MRAS

These drugs (mineralocorticoid-receptor antagonists) have a diuretic effect, important in heart failure where fluid is frequently retained, and also reduce levels of the hormone aldosterone, which raises your blood pressure and can cause other heart and kidney problems.

## USEFUL RESOURCES FOR HEART FAILURE PATIENTS:

- ▶ The Pumping Marvellous Foundation <https://pumpingmarvellous.org/>
- ▶ Heart Failure Matters [https://www.heartfailurematters.org/en\\_GB/](https://www.heartfailurematters.org/en_GB/)
- ▶ Cardiomyopathy UK (for diseases of the heart muscle) <https://www.cardiomyopathy.org/>



# ARRHYTHMIA (CARDIAC RHYTHM MANAGEMENT)

Data from the National Audit for Cardiac Rhythm Management

## QUICK FACTS

- ▶ The first pacemaker implantation was performed in 1958.
- ▶ There are 187 UK hospitals carrying out device implantation and 75 carrying out ablations.
- ▶ There were 45,852 devices implanted in the reporting year 2016/17.
- ▶ There were 19,319 ablations carried out in the reporting year 2016/17.

An **arrhythmia** is a disorder of the heart rhythm, and **cardiac rhythm management** is the treatment. As we saw in the introduction on page 5, the pumping of your blood around your body is controlled by the powerful electrical conduction system in your heart. If there is an irregular rhythm (arrhythmia) this can cause serious problems, even leading to **sudden cardiac arrest (SCA)** where the heart stops completely, which is often fatal (see fact box). Many arrhythmias are manageable with medication or technological solutions such as pacemakers or implantable cardioverter defibrillators (ICDs) to regulate the rhythm of the heart, and modern techniques such as ablation, where the problem electrical pathways are destroyed so they cannot influence the heart's rhythm. This is particularly recommended for the most common arrhythmia **atrial fibrillation (AF)** (see fact box).

## TYPES OF DEVICE

The most common type of device implant is the **pacemaker**, which is a small device, usually with one or more leads, implanted just under the collar bone, which artificially takes over the function of your heart's natural pacemaker, the sinus node. They work by continually monitoring the rhythm of your heart. If and when it beats too slowly or too fast the pacemaker returns the heart to its normal rhythm. Technological advances have led to the development of more complex devices, such as **implantable cardioverter defibrillators (ICDs)** which fulfil the pacemaker function and can also shock the heart into a regular rhythm when it becomes dangerously

irregular. There are also **cardiac resynchronisation therapy (CRT)** devices which are often used to treat heart failure, when the heart becomes enlarged and contraction happens at different times on each side. An electrical impulse is sent to both sides of the heart so that they contract at the same time, or with some devices both sides of the heart can be shocked into contracting regularly. These types of devices improve weak heart function in heart failure patients, making symptoms easier to live with, as well as managing rhythm problems.

## ATRIAL FIBRILLATION (AF)

Atrial fibrillation (AF) is the most common arrhythmia, with 1.5 million people diagnosed and another 500,000 unaware that they have AF. AF can be permanent or come and go, and is caused by extra irregular electrical responses which cause the atria (the top two chambers) of your heart (see the diagram in the introduction on page 5) to quiver (known as "fibrillation"). You can often experience palpitations, breathlessness, dizziness or fatigue when this happens, but some people do not experience any symptoms. When the chambers of the heart are not in rhythm the blood flow is irregular and blood clots can form. If a clot travels to the brain this can lead to an AF-related stroke. AF-related strokes are the most common, often most disabling or fatal, type of stroke. To prevent an AF-related stroke occurring, anti-coagulation medication is prescribed. However, to treat the symptoms

of AF drugs or techniques such as ablation (see above) are used, or an implantable device such as a pacemaker.

## SUDDEN CARDIAC ARREST

As we saw in the introduction on page 5, electrical signals sent by the system which powers your heart keep it beating and blood pumping around your body. If this system completely stops working for any reason, such as a chaotic abnormal heart rhythm developing, blood will stop being pumped and your brain is starved of oxygen, and you will become unconscious. You will often stop breathing.

Cardiac arrest is described by the British Heart Foundation as “the ultimate medical emergency”. This is especially so if it happens outside hospital. A few minutes of giving the right treatment can literally be the difference between life and death. Some arrhythmias can be fatal – ventricular tachycardia (VT) or ventricular fibrillation (VF). When this happens the heart rhythm becomes chaotic and rapid. Without the intervention of **cardiopulmonary resuscitation (CPR) and the use of an automated external defibrillator (AED)** the person is likely to die suddenly and unexpectedly.

CPR provides a 9% chance of survival, however when the person suffers ventricular tachycardia or ventricular fibrillation, the only chance of survival is with CPR + AED which provides more than a 50% chance of survival. Only with an AED shocking the heart rhythm back to normal will the person survive a sudden cardiac arrest.

It is vitally important that both CPR + AED are used in these circumstances, and everyone should make themselves aware of their nearest AED. For every minute that passes whilst a person is in VF or VT they

have 10% less chance of survival. Therefore whilst waiting for paramedics to arrive it is important to perform CPR and use an AED to save a life.

Check for a pulse and observe whether the person appears to be breathing, call 999 as soon as you can and ask for an ambulance immediately and they will advise where you can find the nearest AED, or see the link on page 20 if you want to find the nearest one to your workplace or home. There is also a link to find out where you can learn CPR. Not all AEDs are listed with local ambulance services so it is important to familiarise yourself with your nearest AED and also to contact the local ambulance service. You can also search at <http://www.heartrhythmalliance.org/aa/uk/defibs-save-lives>.

Most patients with pacemakers and other devices need no further procedures throughout the many years until the battery needs changing. However, occasional complications can arise in the first weeks or months after the implant procedure, and these may need to be corrected with a further procedure (such as repositioning of a lead that has become dislodged in the first few days, or removal of the device due to infection).

In the UK, we have found that following a first pacemaker implant, **4.2%** of pacemaker patients require another procedure within a year, usually because of a complication. For complex devices (ICD and CRT) this figure is **6.3%**.

Some patients undergoing ablation also require a second procedure, but this not because of a complication, rather because their arrhythmia recurred (i.e. the original procedure was not completely effective). Based on the 29 UK hospitals where this could be analysed, a further procedure was required within 1 year following **3%** of simple ablations, and following **10.3%** of ablations for atrial fibrillation (AF).

Depending on the type of device and the patient, most device batteries last for 6-10 years. A few months prior to the battery running out, the entire device is replaced and connected to the existing lead(s) – this is known as a “**box change**”.

## USEFUL RESOURCES FOR PATIENTS WITH ARRHYTHMIA:

- ▶ Arrhythmia Alliance <http://www.heartrhythmalliance.org/aa/uk>
- ▶ <https://www.bhf.org.uk/informationsupport/conditions/abnormal-heart-rhythms>
- ▶ Sudden Cardiac Arrest <https://www.suddencardiacarrestuk.org>

# CONGENITAL HEART DISEASE

Data from the National Congenital Heart Disease Audit

## QUICK FACTS

- ▶ At least 8 in 1000 babies are born with a heart or circulatory condition.
- ▶ There were 3,951 operations on children under 16 in 2017/18 for congenital heart disease.
- ▶ In total there were 12,247 congenital heart disease procedures on children and adults in 2017/18.

Many heart problems develop during a person's lifetime and are influenced by lifestyle as well as genetics, but some, called **congenital heart disease**, are present from birth, and develop in the womb.

As a new or expectant parent this will obviously be a frightening thing to hear, but techniques, care and understanding have advanced significantly over the past few decades so that the vast majority of babies survive well into adulthood with a good quality of life. Some congenital heart disease problems self-correct over time (such as small ventricular septal defects (holes in the heart)), and others do not need surgery and can be monitored and managed with medications if necessary.

Research has shown that congenital heart disease is managed better when it can be diagnosed before birth, at the routine scan offered to all pregnant women at 20 weeks. The heart's structure has developed as early as 10 weeks of pregnancy and most major problems with the structure of the heart can often be detected with the ultrasound scan at the 20 week scan or even earlier.

For children who go on to need a procedure in the first year of life, over half (**53.5%**) of their congenital heart problems are currently picked up by the scan.

As a baby grows in its mother's womb a number of congenital heart conditions can develop. A few of these are:

**Hole in the heart** – this is where there is an opening in the wall that separates either the filling or pumping chambers of the heart (or both). These holes affect the flow of blood through the heart so that extra blood goes into the lungs and, if large, may lead to breathlessness and failure of the baby to grow. Not all holes will need treatment and some small ones will

close on their own in time (up to 20 years). However if surgery is needed it is generally in infancy or early childhood, whilst some holes can be closed using a transcatheter device ('keyhole' procedure), usually by mid to late childhood. There is a need for subsequent monitoring through life, although further procedures are unlikely to be required later in life if no other congenital heart condition is present.

**Hypoplastic left heart syndrome (HLHS)** – a relatively rare condition where the left side of the heart does not fully develop, and is much smaller. Multiple surgical procedures may be required in infancy and early childhood. It is often possible to detect it in pregnancy, and **93%** of the babies with this condition who had to have a procedure before 6 months of age had their condition detected before birth in 2017/18 in the UK and Republic of Ireland.

**Transposition of the great arteries with intact ventricular septum (TGA-IVS)** – in a healthy heart the pulmonary (lung) artery is connected to the right pumping chamber (right ventricle) which pumps the blood to the lungs, whilst the left pumping chamber (left ventricle) pumps the blood around the body through the aorta (the body's main artery). However, in this condition they are switched, and both great arteries are connected to the wrong pumping chambers. This means that the blood being circulated around the body is low in oxygen and the baby is 'blue' at birth. It's likely that the baby will need an operation in the first couple of weeks of life. Again, this condition is often visible on an ultrasound scan at 20 weeks of pregnancy and in 2017/18 **75.8%** of babies with this condition, who had to have a procedure before 6 months of age, had it detected before birth in the UK and Republic of Ireland.

There can also be combinations of structural problems in different areas of the heart.

## ANTENATAL DETECTION

Still nearly half of children needing a procedure before 1 year of age were diagnosed antenatally (49.5%)

Transposition of the great arteries with intact ventricular septum (TGA-IVS) - **93%** of children needing procedure before 1 year of age were diagnosed antenatally

Hypoplastic Left Heart Syndrome (HLHS) - **75.8%** of children needing procedure before 1 year of age were diagnosed antenatally



The overall survival rate for the 3,951 surgical operations undertaken in children under 16 years of age in 2017/18 was **98.6%**. However, assessing the likely survival rate for a specific congenital heart problem at a particular centre with its clinical team is more complex. To estimate the likelihood for each hospital, the congenital heart disease audit programme uses a risk-based calculation to take into account the type of congenital heart disease as well as non-cardiac patient factors, such as genetic abnormalities and how sick the child is just before the operation, as these all influence the outcomes after a given procedure. You can read more about this and view the risk-adjusted survival rates for all UK congenital heart disease centres [here](#).

## USEFUL RESOURCES FOR CONGENITAL HEART DISEASE PATIENTS:

- ▶ Tiny Tickers [www.tinytickers.org](http://www.tinytickers.org)
- ▶ Children's Heart Federation <http://www.chfed.org.uk/>
- ▶ Little Hearts Matter <https://www.lhm.org.uk/>
- ▶ The Somerville Foundation (adults with congenital heart problems) <https://thesf.org.uk/>
- ▶ Antenatal Results and Choices <https://www.arc-uk.org/>



# USEFUL RESOURCES

## SUPPORT FOR CARERS

- ▶ <https://www.nhs.uk/conditions/social-care-and-support-guide/introduction-to-care-and-support/>
- ▶ <https://carers.org/our-work-locally>

## MENTAL HEALTH

Mental health issues go hand in hand with life changing health events. Post-traumatic stress disorder (PTSD), anxiety and depression can seem overwhelming but there is support available.

- ▶ <https://www.nhs.uk/conditions/stress-anxiety-depression/free-therapy-or-counselling/>
- ▶ <https://www.samaritans.org/>
- ▶ <https://www.mind.org.uk/>
- ▶ <https://www.bhf.org.uk/information-support/support/health-and-emotional-support/coping-with-anxiety-and-depression>
- ▶ <https://www.thecalmzone.net/>

## SHARED DECISION MAKING

Until fairly recently most medical decisions were made solely by the consultant, GP or nurse. But nowadays patients are encouraged to discuss the pros and cons of the treatment that a doctor has recommended. The advantage of this is that it can take into account the patient's concerns and their overall situation, rather than just focusing on the medical issues. Sometimes what a doctor or nurse thinks is best for the patient can differ from what the patient actually wants. The decision making process is a two-way dialogue, so it is "shared".

- ▶ <https://www.england.nhs.uk/shared-decision-making/>
- ▶ <https://www.sarawickham.com/questions-and-answers/what-is-the-bran-analysis/>

## NHS APPS

The NHS has launched a portal and range of apps to help manage your health.

- ▶ <https://www.coordinatemycare.co.uk/>
- ▶ <https://www.nhs.uk/apps-library/>
- ▶ <https://www.england.nhs.uk/personalisedcare/social-prescribing/>

# FREQUENTLY ASKED QUESTIONS

## WHAT QUESTIONS SHOULD I ASK MY DOCTOR?

<https://www.bhf.org.uk/information-support/heart-matters-magazine/medical/questions-to-ask-your-doctor>

## HOW DO I UNDERSTAND MY RISK OF SOMETHING HAPPENING TO ME?

Reports in the media often carry stories about health risks in numbers or percentage terms. This can be misleading or confusing and concern people. Ask your doctor whether the numbers you have been given are the absolute risk (the risk to anyone of a given outcome) or the relative risk (to you as an individual having a particular condition or treatment). Then you can make a more informed decision. More information here:

▶ <https://www.eufic.org/en/understanding-science/article/absolute-vs.-relative-risk-infographic>

## HOW CAN I LEARN CPR?

The British Heart Foundation's HeartStart network of voluntary organisations provides free or inexpensive training in CPR to individuals and groups. Access the location search here. St John's Ambulance also provides instruction.

▶ <https://www.bhf.org.uk/how-you-can-help/how-to-save-a-life/cpr-training-in-communities/heartstart-communities>

▶ <http://www.sja.org.uk/sja/training-courses/first-aid-courses/defibrillator-and-cpr.aspx>

## WHERE IS MY NEAREST PUBLIC DEFIBRILLATOR (AED)?

Currently Heartsafe has the most complete list of AEDs in the UK.

▶ <http://heartsafe.org.uk/AED-Locations>

Try the **GoodSAM** app which will show you defibrillators close by on your mobile phone. You can also upload a picture of an unlisted defibrillator you spot when you are out and about. Many defibrillators haven't been registered with the local ambulance service, so this is a good way of flagging them up.

▶ <https://www.goodsamapp.org/aed>

## WHAT CAN I DO TO KEEP MY HEART HEALTHY?

The BHF Heart Matters magazine is a comprehensive and engaging resource for healthy lifestyle tips and personal stories about living with heart conditions.

▶ <https://www.bhf.org.uk/information-support/heart-matters-magazine>

▶ <https://www.nhs.uk/live-well/eat-well/the-eatwell-guide/>

▶ <https://www.nhs.uk/live-well/exercise/>

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