National Cardiac Audit Programme



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# National Cardiac Audit Programme

# 2023 Annual Report for Patients, Carers and the Public

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## About this report

This patient report is designed as a companion to the 2023 National Cardiac Audit Programme (NCAP) report produced by the National Institute for Cardiovascular Outcomes Research (NICOR). NICOR is commissioned by NHS England and GIG Cymru/NHS Wales to complete national cardiac audits to inform healthcare providers and research organisations.

The primary aim of the 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 2023 NCAP annual report and other key documents via the <u>NICOR website</u> covering data from 1 April 2021 to 31 March 2022. For some measures, three years' data are considered (2019/20 – 2021/22).

# How to use this report



# The report is divided into six areas of clinical expertise (called "domains") audited by NCAP.

We have summarised key findings from the full 2023 annual report, provided useful background information and highlighted what you can do to help improve cardiac health for you, your friends and family.

We have also included answers to some frequently asked questions and links to further information or support. If you would like to read specific parts of the annual report, there are links to all six domain summaries.



# Why do we audit hospital services?

## Our primary aim is to support clinical improvement programmes in hospitals to improve patient outcomes and quality of care.

The information routinely collected from clinical audits is used for quality improvement and quality assurance purposes. The audit work we carry out at NICOR helps the NHS to define the standards used for evidence-based cardiac healthcare and to monitor whether those standards are being met. Where standards are not met, we recommend actions to help hospitals and medical professionals improve their performance. The report also enables large healthcare organisations and commissioners to understand the national picture.

## The UK in numbers:

- 7.6 million people are living with heart and circulatory diseases
- every three minutes someone dies from a heart or circulatory disease
- 13 babies a day are diagnosed with a congenital heart defect
- 260 hospital admissions a day are due to a heart attack\*.

The national audit data are also useful for public health research, the findings of which may then become important for the audit programme. Many discoveries which have improved millions of lives worldwide have been made by analysing patient data, or the patient data have highlighted important trends 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. Today in the UK, 80% of the cardiovascular disease burden can be attributed to modifiable risk factors, such as diet, smoking or high blood pressure. See our infographic in the <u>2021 report</u>.

\*Figures from British Heart Foundation https://www.bhf.org.uk/what-we-do/our-research/heart-statistics

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# Foreword from the NICOR Patient Representative Group Chair, Sarah Murray

## "We live in troubling times and the spotlight is brightest upon healthcare. Post pandemic there was focus on getting services back up and running after coming to a virtual standstill.

Last year's report reflected that during this time there was innovation and clever ways of working to help the very sick receive care despite the pandemic waves.

This report highlights the wake of the disruption. The most startling but unsurprising outcomes were the stories of appointment and operation cancellations - often multiple times - and the effect these setbacks have had on patients' physical health and wellbeing as well as their financial health and inability to get back to work. Carers also take the strain, supporting families as well as the sick. It is, quite literally heart-breaking.

In the midst of all this there are glimmers of hope

that show some services are back on track and new ways of working and innovation are being deployed. These may help the services regain some ground and positive stories of wonderful care from the NHS have emerged. But this is not enough.

We have a backlog of sick and dying patients who need care, and they need it now not next year or in a few months' time. The challenge is massive. It could be you; it could be me - we are all potential patients, and we need to do all we can to highlight the issues and hold the NHS to account.

This report makes for sober reading and the challenges are laid bare - let's meet them."



Sarah

**Cardiac healthcare:** recovering from the COVID-19 pandemic but delays to essential treatment need to be addressed

The focus of this year's report has been on the time delays and waits for treatment, and the challenges of urgent care post-COVID-19.

We published a <u>report</u> on the impact of COVID-19 on cardiovascular care in September 2020 which encompasses much of the first and second waves of the pandemic. We have learned to accept and understand COVID-19, assisted by vaccine-induced and natural immunity. The healthcare services are also in recovery, aiming to reach prepandemic levels of activity and meet national targets. We have spoken to some patients and carers to hear their experiences following the first and second waves of the pandemic and these have been published on our <u>website</u> and are available to read on <u>page 26</u>.

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

## FACT BOX: COVID-19 PANDEMIC RECOVERY

### Number of recorded heart attacks rise as more people seek urgent care

Last year in 2020/21 we saw a drop in the number of recorded heart attacks, believed to be because patients were less likely to seek urgent medical care because of the COVID-19 pandemic. For 2021/22 levels have returned to pre-pandemic levels with a 16% increase in the number of confirmed heart attacks recorded (85,650). This includes lower risk heart attacks (called <u>NSTEMI</u>) with over 55,000 of these events recorded in the audit and just over 30,000 higher risk heart attacks (called <u>STEMI</u>). These figures reflect that people have learnt to accept and understand COVID-19, assisted by vaccine-induced and natural immunity, and are more likely to seek urgent medical care, not because we are seeing more heart attacks than usual.

## Worsening delays to emergency (STEMI) treatment

The <u>MINAP audit data for 2021/22</u> shows however, that there are worsening delays for patients with higher risk heart attacks, mostly because of delays seen before arriving at hospital to receive the emergency care they need. The proportion of patients receiving primary <u>percutaneous</u> <u>coronary intervention (PCI)</u> for STEMI fell to only 30% within 120 minutes from calling for help (down from 55% in 2020/21), with just over half (55%) treated within 150 minutes. These waits can have serious consequences for patient outcomes.

## Delays for patients referred for urgent angiography and treatment

National guidelines state that patients with the lower risk (NSTEMI) heart attacks should receive angiography within 72 hours of admission. In 2020/21, 66% underwent <u>angiography</u> within 72 hours of admission to hospital (a significant increase in proportion compared to 55% in 2019/20). However, only 56% of eligible patients with NSTEMI received an angiogram within 72 hours in 2021/22, so overall performance has fallen back to just above pre-pandemic levels.



## FACT BOX: COVID-19 PANDEMIC RECOVERY

### More patients self-presenting at hospital rather than via the ambulance

Around 19% of heart attack patients are attending hospital via their own means of transport instead of using an ambulance (an increase from previous years). Ambulance services, like all NHS services across the UK, have been experiencing long waits and delays. This includes exceeding national targets for response times and handover delays, which is due to the level of demand, hospital capacity, staffing pressures and other complex factors. Patients may not be willing to wait for the ambulance service to respond as they might feel they can get to hospital more quickly by arranging their own transport. This can have a negative consequence on the patient's outcome due to not receiving the specialist, life-saving skills from the paramedics while being transported and because attending an Accident & Emergency (A&E) department can cause delays to treatment whereas the ambulance services take the patient directly to the specialist team needed for treatment. For patients requiring primary PCI, the proportion who self-presented to hospital increased from 4% in April 2021 to 8% by March 2022 [Figure 1].

### Patients referred to cardiac rehabilitation programmes are at highest recorded level

Patients referred to cardiac rehabilitation programmes following a heart attack and the proportion of patients receiving an echocardiogram prior to discharge from hospital are at the highest recorded level. The number of referrals to rehabilitation exceeds the 85% target of patients to be referred.

The provision of an echocardiogram prior to discharge is at its highest recorded level, at 82% in 2021/22, compared to 63% in 2012/13 – a significant improvement. The echocardiogram reveals how well the heart pump is working and this helps doctors decide which medications the patient should receive.



# **Figure 1:** Proportion of patients undergoing primary PCI who self-presented to hospital, 2018/19 - 2021/22 [MINAP data]

## Care of heart attack patients

Place of care and access to specialists is important for heart attack patients, as it is for heart failure patients (see <u>page 18</u>). With the lower risk type of heart attacks, 64% of patients in 2021/22 were admitted to a cardiology ward, and 97% seen by a cardiologist. 89% of all heart attack patients were discharged home with all drugs for which they were eligible, this being a small decline from 90% in 2020/21. More than 85% of all heart attack patients who were discharged home were referred to a cardiac rehabilitation programme in 2021/22, continuing an upward trend.



## **USEFUL RESOURCES FOR HEART ATTACK PATIENTS:**

<u>Heart UK (cholesterol charity)</u> <u>NHS conditions: Heart attack and recovery</u> <u>British Heart Foundation: Heart attack</u>



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

## FACT BOX: COVID-19 PANDEMIC RECOVERY

## On the road to recovery with more PCI procedures carried out

The number of PCI procedures in the UK has risen to 97,765 in 2021/22, which is an increase from 90,708 in 2020/21. However, PCI activity has not quite returned to the pre-pandemic levels of 100,112 in 2019/20. There was an increase seen across the UK, except for Scotland, where figures remained unchanged. There was an 8% rise in England, 12.1% rise in Northern Ireland and 7.7% rise in Wales. The increase in the number of PCI procedures reflects the increase in the number of confirmed heart attacks and the restoration of elective planned PCI for patients with angina, which had been put on hold in the early phase of the pandemic [Figure 2].

## Patients continue to receive PCI treatment in both low and high-risk heart attacks

2021/22 saw a 16% increase in the number of confirmed heart attacks, and despite the increase in the number of patients, high rates of PCI were delivered for both STEMI and NSTEMI cases. The number of patients who received reperfusion treatment, mainly primary PCI, remained high at 84%. Patients with NSTEMI (the lower risk heart attack) eligible for PCI before hospital discharge increased slightly to 83%, a similar level to that seen over the last five years.

## Number of day cases continue to rise

Over the last year the number of elective PCI procedures treated as a day case has risen to 71% in 2021/22, an increase from 64% in 2018/19. However, it is noted there is significant variation with some hospitals performing day case PCI in almost all elective cases, and some where almost all patients are kept in hospital overnight following their procedure.

## If you experience a high-risk heart attack, the preferred treatment in the UK is emergency or primary PCI <u>(also known</u> <u>as primary angioplasty)</u> to restore blood flow to the heart as soon as possible to stop further damage.

The ambulance will normally take you to 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 teams who are used to seeing heart attack patients and performing the PCI procedure as an emergency treatment.

As reported, there has been an increase in the number of patients who are self-presenting to hospital, possibly because the ambulance service is under unprecedented pressure (page 8).

## The advice is that you should always dial 999 if you experience symptoms of a heart attack.

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 and, if there are no available facilities on site, you will need to be transferred by ambulance to the nearest hospital which can perform the PCI procedure. Even if you have attended a hospital with PCI services, it takes time from the first evaluation by the A&E staff to be referred on to the specialist teams who will treat you. Either way, this can cause unnecessary delays to you getting the treatment you need.

Another important reason for calling an ambulance rather than taking yourself to your local hospital's A&E department is that if a heart attack is suspected the ECG test can often be carried out by paramedics at your home. This ensures not only that you are taken to the correct hospital (a heart attack centre – see above) but also that they will be warned you are on the way, saving precious time so that you can undergo the most appropriate treatment as quickly as possible.

## 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 safer, with less risk of complications than in the past. 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 an eye on patients overnight.



# Figure 2: Total PCI procedures in England and Wales by month, against number of monthly UK COVID-19 admissions, 2021/22 [NAPCI and UKHSA data\*]



\*UKHSA = UK Health Security Agency. https://coronavirus.data.gov.uk/details/healthcare

## **USEFUL RESOURCES FOR PCI PATIENTS:**

British Heart Foundation: Treatments for heart conditions, angioplasty – your quick guide

**NHS: coronary angioplasty and stent insertion** 

**British Cardiovascular Intervention Society** 

• 111111





## With data from the National Audit for Adult Cardiac Surgery (NACSA)

## FACT BOX: COVID-19 PANDEMIC RECOVERY

#### Recovery is slow for the number of heart operations performed

In 2021/22, 24,807 adult heart operations were performed, a 16% reduction in the number of operations performed compared to 2019/20 (the year prior to the COVID-19 pandemic). However, this is an improvement compared to last year, where only 19,333 adult heart operations were performed (a 34% drop from 2019/20). It's estimated that around 5,000 patients did not have heart surgery who should have done and the number of operations that could be performed last year varied substantially between hospitals, from 115% to 43% of pre-pandemic levels, with only four hospitals achieving at least 100% of their 2019/20 figures. Across the UK, activity in 2021/22 averaged 84% of pre-pandemic levels. The NACSA no longer incorporates data from Scotland as Scottish hospitals send their data to the Scottish Cardiac Audit Programme.

### Waiting times for elective surgery improving, but not to pre-pandemic levels

The first year of the pandemic saw the average waiting time for elective cardiac surgery in England increase to 127 days in 2020/21 from 104 in 2019/20. Over the last year there have been improvements and a reduction in the average wait time, to 114 days. The same can be seen in Wales where the average waiting time has reduced to 109 days in 2021/22 compared to 130 days in 2020/21. However, in Northern Ireland waiting times continue to increase and are now on average 199 days, up from 122 days pre-pandemic.

#### **Emergency aortic surgery not impacted by COVID-19 and number of operations rises**

Emergency operations on the thoracic aorta increased from 382 cases in 2013/14 to 644 cases in 2021/22, a 68% increase over this time and the trend has not been impacted by COVID-19. A campaign, 'Think Aorta', aimed to raise awareness of the diagnosis of aortic dissection (when a tear in the wall of this major vessel occurs) by primary care and emergency physicians, and the transfer of patients to specialist cardiac surgical centres for treatment has supported this rise in the number of cases, rather than a significant increase in the prevalence of the disease in the UK.

# Waiting times for urgent coronary artery bypass graft (CABG) procedures are worse, with no hospital achieving the 7-day target

The optimum time for surgery for urgent CABG is between five to seven days following the diagnostic test (the angiogram) which reveals the need for surgery. Treatment is delayed for this period to allow certain medications to be stopped which reduces the risk of bleeding during surgery. In 2021/22, waiting times have increased by two days in England (to 12 days). In Northern Ireland waiting times have also increased by seven days (to 27 days). However, in Wales waiting times have improved by three days (to 14 days). No hospital achieved the 7-day target, compared to three hospitals in 2020/21.

## Day-of-Surgery Admission (DOSA) rates for elective operations remain below prepandemic levels and only one hospital achieved the 50% target

In 2018, the proportion of patients having DOSA for elective surgery almost doubled from 11% to just under 21% across England. The COVID-19 pandemic saw a reduction in face-to-face preassessment clinics and as a result the number of DOSAs fell. Since the pandemic there has been a challenge to reinstate or improve the number of DOSAs compared to levels in 2020. DOSA numbers fell in 2020/21 across England to under 9% and have improved a little in the last year, back to 11%. The figures were much lower in Northern Ireland (1.7%) and Wales (0.6%). DOSA numbers vary significantly between NHS hospitals, from 0% to 55% [Figure 3].

DOSA provides a better patient experience and supports efficiency for hospitals. It is also more likely that fewer patients will require cancellation for medical reasons if they have been carefully assessed prior to admission. An increase in the number of DOSAs will help support the recovery of services after the challenges seen over the last two years.

# **Figure 3:** Proportion (%) of patients with day-of-surgery admission (DOSA) for elective CABG, by NHS hospital, 2021/22 [NACSA data]



## Adult Cardiac Surgery includes all procedures performed on patients aged 18 or over that involve the heart or <u>structures attached to the heart.</u>

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 <u>Coronary Artery Bypass graft (CABG)</u> <u>procedures; valve replacement or repair;</u> <u>aortic surgery (surgery on the body's main</u> <u>artery</u>); 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.

2021/22 saw 1,910 fewer CABGs, (a 15% reduction) performed compared to pre-pandemic levels. Coronary revascularisation rates (i.e. CABG and PCI rates combined) also remained below pre-pandemic levels last year. Over 4,000 fewer procedures were performed, a 4% reduction compared to 2019/20.

# USEFUL RESOURCES FOR ADULT CARDIAC SURGERY PATIENTS:

British Heart Foundation: coronary bypass surgery

British Heart Foundation Heart Matters Magazine: valve disease

**British Heart Foundation: aortic aneurysm** 



# **Heart failure**



## With data from the National Heart Failure Audit (NHFA)

## FACT BOX: COVID-19 PANDEMIC RECOVERY

#### Heart failure admissions remain lower than pre-pandemic levels

Records were submitted on almost 84,000 admissions, an increase of 15% of patients presenting at hospital with suspected heart failure from last year. However, there was only a 3% increase in the number (63,644) of validated admissions for primary heart failure in 2021/22 compared to levels in 2020/21. This is fewer than before the pandemic in 2019/20 (69,500).

### Fewer than half of patients were admitted to cardiology wards and inequalities seen

The number of patients admitted to cardiology wards in 2021/22 remains consistent with 2020/21 with a slight drop from 48% to 47%. Patients aged over 75 years were less likely to be admitted to a cardiology ward with 42% admitted compared to 57% for those aged under 75. There was a similar inequality with men and women. Women had less access to cardiology wards at 42% compared to 51% of men in 2021/22. Only 14% of hospitals across England and Wales achieved the national target of 60% of heart failure admissions being managed in a cardiology ward.

### More patients on a general hospital ward should be seen by the heart failure team

At least 80% of patients admitted with acute heart failure should be seen by a member of the specialist heart failure team. In 2021/22, 59% of hospitals met the target of 80%, a decrease by 6% since 2020/21. There is considerable variation with many hospitals having fewer than 50% seen by a specialist team.

## FACT BOX: COVID-19 PANDEMIC RECOVERY

## More patients should be offered specialist follow-up and rehabilitation

All patients discharged should ideally leave hospital knowing when, where and by which member of the specialist heart failure team they will be reviewed within two weeks. They should also be referred to cardiac rehabilitation. The uptake of cardiac rehabilitation has been hugely impacted by COVID-19 and ongoing hospital pressures. Just under 10% of patients in 2021/22 were referred for cardiac rehabilitation during hospitalisation. Rates are higher for those cared for in cardiology wards (15%), a decrease of 3% from 2020/21, compared to 6% for those seen on general medical wards (a decrease by 2%). However, it should be noted many more patients are now referred to community teams and this audit does not capture these data.

## 30-day mortality improved

In 2020/21 the 30-day mortality rate rose to 16%, this has since improved and in 2021/22 the rate reduced to 14%. The increase seen last year may have been a result of shorter length of stays due to the pandemic with more unstable patients being discharged earlier from hospital. The improvement may also reflect the return of specialist heart failure team members post-pandemic and improved discharge planning and transitional support offered.

# Heart failure occurs for a number of reasons.

Heart failure occurs for a number of reasons. It 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 (a disease of the heart muscle). as well as other causes. It cannot be cured but, in many cases, patients can manage their condition with drugs and other therapies. When the heart pump function is weaker than usual, this is referred to as Heart Failure with reduced Ejection Fraction (HFrEF), the ejection fraction being a marker of how well the pump is functioning (the higher the number the better). In some patients the mechanism for the symptoms is different as the heart pump function appears to be normal or near normal. This is referred to as Heart Failure with preserved Ejection Fraction (HFpEF).

The place of care is important for patients, as being seen on a cardiology ward is associated with the best survival (during admission and after discharge) and the best access to specialist care (see the graphic on the next page).



## Hospitalisation for heart failure 2021/22

Access to Cardiology wards and Specialist HF care is associated with better survival and improved treatment at discharge for those with HFrEF.

## Age and sex of heart failure patients

The average (mean) age of a heart failure patient was **77.7** years old in 2021/22. Men are typically younger than women when admitted to hospital with heart failure with an average age of **75.9** years compared to the female **80 years**.

	<b>63,644</b> Validated admissions	All patients	Seen by a specialist	Admitted to a Cardiology Ward
۲	Patients diagnosed with echocardiography	85%	89%	92%
J.	Patients receiving specialist care	82%	100%	99%
	Patients with HFrEF discharged on all three disease-modifying drugs	56%	59%	65%
	Patients who received a cardiology follow up	32%	35%	44%
	Patients who received a <b>Heart Failure nurse</b> follow up	58%	64%	69%
	Patients referred to cardiac rehabilitation	10%	11%	15%
	Mortality in Hospital	9%	8%	6%

Place of care is a key quality indicator for HF as care on a cardiology ward is associated with the best survival, both during admission and after discharge, better treatment for HFrEF and the best access to specialist care.

## Drug therapy for heart failure

There are three groups of drugs which have been shown to improve survival for heart failure patients where there is impairment of the pump function of the heart. Such 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 (48% for the most common form of heart failure) than a patient discharged on all three drugs (82%) (data from 2019/20 as the latest data available). In 2021/22, 56% of patients were discharged on all three drugs, an improvement from last year (52%). This varied by whether the patient had access to specialist care as only 27% of patients who had no heart failure specialist care were prescribed all three drugs, irrespective of which ward they were treated on.

## The three groups of drugs are:

ACE Inhibitors (ACEIs), Angiotensin Receptor Blockers (ARBs) and Angiotensin Receptor/Neprilysin Inhibitor (ARNI). These were prescribed to 87% of patients with the most common form of heart failure in 2021/22. Taking one of these drugs can often ease this narrowing of the vessels and lower your blood pressure. Watch this video from the British Heart Foundation <u>'How do ACE inhibitors work?'</u>

Beta blockers (prescribed to 90% of patients with the most common form of heart failure in 2021/22).

Most beta blockers have names ending in 'lol' such as carvedilol, propranolol, bisoprolol.

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 <u>'How do Beta Blockers Work?'</u>

Mineralocorticoid Receptor Antagonists (MRAs) (prescribed to 63% of patients with the most common form of heart failure in 2021/22).

These drugs (mineralocorticoid-receptor antagonists) have a diuretic effect, important in heart failure where fluid is frequently retained. See this description from <u>Heart Failure Matters.</u>

## **USEFUL RESOURCES FOR HEART FAILURE PATIENTS:**

The Pumping Marvellous Foundation

Heart Failure Matters

Cardiomyopathy UK (for diseases of the heart muscle)





## With data from the National Audit for Cardiac Rhythm Management (NACRM)

## FACT BOX: COVID-19 PANDEMIC RECOVERY

## Steady recovery in implanting of pacemakers and other electronic cardiac devices

In 2021/22 we reported an 11% increase in total number of devices implanted compared with 2020/21. This represents a steady improvement from the 17% drop seen in 2020/21 compared to 2019/20. Overall activity remains 7.7% less than prior to the pandemic, but recovery is going in the right direction. Reducing the waiting lists will continue to be challenging until device activity returns to pre-pandemic levels.

## Use of leadless pacemakers increased dramatically

There have been some notable trends in <u>leadless cardiac pacemaker (LCP)</u>. The number of reported LCP procedures did not change in the two years prior to the pandemic but has increased sharply since. This is likely to be due to technology advancements, an increase in the number of devices available and access to the devices [Figure 4].

## Improvement to catheter ablation rates, but waiting lists affecting patient outcomes

<u>Catheter ablation</u> as a treatment for arrhythmias (especially atrial fibrillation) had been increasingly common in recent years. However elective ablations dropped dramatically by 90% in April 2020 in comparison with 2019/20, due to the first COVID-19 wave. There were just over 18,000 catheter ablations carried out in 2021/22 compared to 13,340 in 2020/21, but still 11% lower than in 2019/20 (19,770).

Unfortunately, the impact in the reduced number of treatments has resulted in substantial nationwide waiting lists for patients suffering significant symptoms, and for some patients the opportunity to have a definitive treatment has probably been missed altogether.

## Figure 4: Leadless cardiac pacemaker procedures, 2015/16 - 2021/22 [NACRM]



## An arrhythmia is a disorder of the heart rhythm, and the treatment for the arrhythmia is sometimes referred to as 'cardiac rhythm management'

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 without medical attention on the scene is often fatal. Many arrhythmias are manageable with medication or technological solutions, such as <u>pacemakers or</u> <u>implantable cardioverter defibrillators (ICDs)</u>, 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.

## Implantable electronic cardiac devices

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'. Despite the COVID-19 pandemic these necessary procedures continued at normal levels during most of 2020/21 and the higher-than-expected device replacement figures from March 2020 data suggest many were brought forward by hospitals in anticipation of pandemic pressures. Implantable cardioverter defibrillators (ICDs, implanted under the skin with a small operation requiring only local anaesthetic) can automatically detect a cardiac arrest, and restore the normal heart rhythm with a shock or with pacing, within seconds. For this reason, they are offered to patients who have been lucky enough to survive a prior cardiac arrest, and those whose heart tests have shown they are at significant risk of a cardiac arrest.



## Catheter ablation

Catheter ablation is carried out by passing a thin catheter into the heart via a vein or artery. It is used to treat some forms of abnormally fast heart rhythms, such as atrial fibrillation. The problem area which is causing the arrythmia is identified, and either thermal (heat) or freezing (cryo) treatment is delivered via the catheter, destroying small areas of tissue and causing scar tissue to form. This can either deactivate the area entirely from the electrical pathways of your heart, so the electricity takes a different route, or stop a damaged area of heart muscle from causing abnormal electrical impulses which make your heart rhythm potentially dangerous.

**A patient's story:** "Mrs X was a 68-year-old lady with a history of atrial fibrillation. She had paroxysmal atrial fibrillation diagnosed early in 2022 when she presented to hospital with breathlessness and presyncope. Her symptoms continued, and when reviewed in outpatients, she was referred to her local centre for consideration of an ablation. Almost 12 months on, she has had three further admissions and had significant weekly symptoms which were not controlled with medication. She was still waiting for an outpatient review at the centre.

Once again, she found herself in her local admissions unit. On this occasion, she was referred to her local centre for consideration of an inpatient ablation. She was accepted for this and spent a further 10 days in hospital before being transferred. She was frustrated that she had to wait in hospital, but realised that if she was discharged again, nothing would progress quickly.

For an entire year, she felt her life had been on hold. Furthermore, she had used considerable healthcare resources. Had delays in the system not built up as a consequence of the COVID-19 pandemic, she could have had the procedure sooner and reduced the risks of further admissions."

## **USEFUL RESOURCES FOR PATIENTS WITH ARRHYTHMIA:**

Arrhythmia Alliance

**British Heart Foundation: Abnormal Heart Rhythms** 

Sudden Cardiac Arrest





## With data from the National Congenital Heart Disease Audit (NCHDA)

## FACT BOX: COVID-19 PANDEMIC RECOVERY

## Increase in number of procedures carried out on children and adults but not back to prepandemic levels

There was a 12% rise in the number of all procedures on children and adults in 2021/22 compared to 2020/21, but the 10,889 procedures reported were still 8% fewer compared to 2019/20. The number of surgical operations on children continued to fall in 2021/22 with 3% fewer surgical procedures compared to 2020/21 and 15% down on figures from 2019/20.

## Waiting lists for less urgent elective procedures continue to increase

The reduction in elective hospital appointments during the pandemic has resulted in substantial increases in waiting times for face-to-face outpatient clinics, both for new and follow-up patients. Hospitals are responding to this by looking at new ways of working including:

- expanding clinic hours with additional clinics at the weekends and accommodating more patients during sessions
- prioritising appointments using patient triage, based on cardiac diagnosis and the need for review, assisted by virtual consultations
- increasing bed capacity by recruiting more staff and evaluating factors such as short notice staff absences and other unexpected causes limiting bed availability.

# Antenatal diagnosis of conditions which need an operation within the first year of life stable

Over the last five years, the rate of antenatal diagnosis seems to have stabilised at just over 50%. The antenatal diagnosis of conditions requiring a procedure in the first year was 50.4% in 2021/22. This is a marginal fall compared to 2020/21 (52.7%) and the 2019/20 levels (51.9). Overall, the level of care has been stable during the pandemic, but without any significant progressive improvement over recent years and levels have plateaued [Figure 5].

Data from Scotland are currently not collected in the National Cardiac Audit Programme as the data are collected by the Scottish Cardiac Audit Programme.

## Figure 5: Antenatal diagnosis in the UK and Republic of Ireland (not including Scotland), 2012/13 - 2021/22 [NCHDA data]



Many heart problems develop during a person's lifetime and are influenced by lifestyle as well as genetics but some, called <u>congenital heart</u> <u>disease</u>, are present from birth and develop in the womb. Some of these conditions include:

<u>Hole in the heart</u>: Not all holes will need treatment and some small ones will close on their own in time (up to 20 years). 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.

Transposition of the great arteries with intact ventricular septum (TGA-IVS): this condition is often visible on an ultrasound scan at 20 weeks of pregnancy. In 2020/21 86.3% of babies with this condition, who had to have a procedure before one year of age, had it detected before birth. This has more than doubled over the last decade from 40% in 2012/13.

#### Complete Atrioventricular Septal Defect

(AVSD): In 2021/22, 56.7% of babies with this condition, who had to have a 'corrective' procedure before one year of age, had it detected before birth. This has risen over the last decade from 37.1% in 2012/13.

<u>Tetralogy of Fallot (TOF)</u>: In 2021/22, 79.7% of babies who had to have a 'corrective' procedure within one year of birth were diagnosed with the condition in the womb. This has risen over the last decade from 32.6% in 2012/13.

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## **Antenatal Detection**

**50.4%** of children needing a procedure before one year of age had their condition diagnosed antenatally.



The overall survival rate for the 3,282 surgical operations undertaken in children under 16 years of age in 2021/22 was 98.4% and remains among the best reported anywhere in the world. 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 on the <u>Children's Heart Surgery website</u>.

# USEFUL RESOURCES FOR CONGENITAL HEART DISEASE PATIENTS:

**Tiny Tickers** 

**Children's Heart Federation** 

Little Hearts Matter

The Somerville Heart Foundation (adults with congenital heart problems)

**Antenatal Results and Choices** 





Including quotes from patient experiences, some patients have asked to remain anonymous and some patients are happy for their first name to be used.

## **Patient experience 1:**

"My father had an aortic dissection in February 2022. An ambulance was not available. He was in absolute agony with heart attack symptoms, and I had to drive from my house to his home and have him physically lifted into my car to take him to the local hospital. This was very traumatic for all involved.



He was monitored for several hours in A&E and then taken off all heart monitors because it was determined he probably had an ulcer... His heart was not monitored until the next morning when he was surrounded by doctors because he had an aortic dissection.

On discharge a 24-hour blood pressure monitoring was not arranged within 14 days as per the discharge letter and I had to go to the hospital to arrange this. A CT scan was to be done within a month and this was not arranged. Again, I had to make efforts to arrange this. My dad phoned the GP to ask for advice and a GP did not speak to him and instead a receptionist told him to go to A&E which would have been completely unnecessary. The GP is almost impossible to contact..."

## **Patient experience 2:**

"As a survivor of a life-threatening aortic dissection, I rely on annual imaging and cardiology follow-up appointments at my NHS specialist aortic centre to monitor my condition and keep me safe (and alive). This usually works well, but during COVID-19 it all fell apart. In 2022, I thought it would all start working again, but I did not receive my annual invitation for a CT scan of my aorta in September.

When I inquired, I was told that I had been discharged, because I had failed to keep an appointment (which I never received). My follow-up cardiology appointment in December was also cancelled (by the hospital). I immediately contacted my cardiologist, who apologised profusely and sorted it all out very quickly. I am reassured that my care is now back on track. I wonder if there has been an increase in Aortic patients 'lost to follow-up' since COVID-19?"



## Patient experience 3:

"I had an extensive dissected aorta and collapsed unconscious in a cab late evening on a Sunday in July 2022. I came round sometime later after having emergency open heart surgery to repair my aorta and spent two weeks in hospital where the care was first class.

I've had nothing but a positive experience both from my GP practice as well as the hospital. I'm having six-monthly scans and appointments, and these are communicated by email and mobile phone. I've also always had detailed reports that also go to my GP.

I've been able to email the consultant's secretary and had very quick responses from the consultant.

On one occasion I had a pain in my shoulder and contacted the secretary. A registrar called me back and said I really needed to come into A&E and have a scan. I arrived in and was sent straight through for the scan.

Another time the consultant sent a long letter to my dentist justifying why I needed antibiotics when having dental work done.

My GP practice has also been excellent, seeing me on the day when I have needed it. I was also referred for genetic testing and I was seen after a couple of months. (My grandfather died of a dissection, so this is now being followed up).

I am aware of the problems within the NHS, but my personal experience is excellent."



## Phil's story:

Phil was diagnosed with heart valve disease after collapsing at work and being rushed to hospital. His valve disease became severe in 2021, and he was scheduled to be treated in August. However, workforce issues at his treating centre meant his treatment was delayed to October, and then November, before he was eventually treated in December. His symptoms had deteriorated, and he was having to take unpaid leave from work to undergo

treatment. The delays led to a more complex surgery, a longer recovery time and an extended stay in hospital - all while Phil was on unpaid leave, placing a huge toll on his family finances.

Phil said: "I just needed to be treated. I knew once I was treated, I could get back to my life, and wouldn't be a strain on the NHS anymore. The strain on my and my wife's mental health during the delays was like nothing I've experienced. This is my heart; it is a serious thing and I needed to be treated. It felt like a ticking timebomb."

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#### Patricia's story:

Patricia was diagnosed with a bicuspid valve as a child and had been monitored regularly throughout her life. She was advised in May 2022 that her valve disease had reached a critical stage and she required surgery. After being told it would be a matter of weeks, which turned into months, before she was eventually treated in February 2023.

Patricia said: "In the nine months from my initial appointment where I was told my severe aortic stenosis needed to be treated to when I was eventually treated, I felt like I was in lockdown again. My life just stopped. I know severe aortic stenosis has bad outcomes after two years, so the further I got into that window the more terrifying it was. The mental trauma of that time was so severe, you just live it all day every day."



## Other sources of information:

A recent article published by the British Heart Foundation (BHF), in response to NHS England figures, shows the number of people on cardiac wating lists is at a record high and patients are waiting over four months for treatment. With nearly 372,803 patients on the waiting lists (February 2023) in England, this is a rise of 60% compared to February 2020, a month before the pandemic began.

Associate Medical Director at BHF, Dr Sonya Babu-Narayan said: "Each month, we are seeing far too many people waiting far too long for time-critical heart care – whether that's hours for an ambulance, too many weeks for a heart test that could unlock life-saving treatment, or even a year for a heart procedure, including heart surgery. Again and again, we are seeing the same tragic story unfold each month - these ongoing and extreme delays to the diagnosis, monitoring and treatment of cardiovascular disease are costing lives and leaving families devastated. "NHS staff are doing all they can, but they are overstretched and there simply aren't enough of them to address the vast and ever-growing backlog of heart care. Heart patients urgently need to hear how their care will be delivered now and in the future. It is vital for the government to immediately publish its long-awaited NHS workforce plan and start addressing this urgent situation." Source: <u>Numbers of heart patients</u> <u>waiting over four months at record</u> high.

In 2022 the BHF published 'Tipping Point', the report covers the two-year period of the COVID-19 pandemic and the impact on cardiovascular care.



## Key points raised in the report:

- Nearly 1 in 5 heart patients told us their health has deteriorated since the start of the pandemic.
- From the beginning of the pandemic to August 2022, there were 30,000 excess deaths involving coronary heart disease in England.
- Over 7,000 people have been waiting more than year for a heart procedure.
- In England there has been a particularly steep decline in hypertension management, with the
  proportion of patients with diagnosed hypertension who had their BP checked falling from 89% in
  March 2020 to 64% by March 2021. This has since partially recovered to 78% by March 2022 –
  good progress, but still not back to pre-pandemic levels.
- Heart patients are still reporting challenges accessing routine care, with 20% of heart patients we surveyed reporting that they have had an appointment for their heart condition cancelled over the last year.
- The total elective care waiting list could increase to 14 million people over the next few years.

The Patients Association's latest survey of patients' experiences of healthcare, 'patient experience winter survey' published in March 2023, shows that when patients are with a healthcare professional their experience is generally positive. However, it also shows many respondents struggled to access the healthcare they needed.



## **Key findings:**

Long waits for appointments were more likely for particular services and types of support. People who struggled to get a GP appointment or ongoing treatment for their condition were more likely to have experienced a long wait to be seen. Three quarters of people (76%) who struggled to be seen at a hospital said that a long wait for an appointment was one of the reasons they faced difficulties. This means that long waits for a hospital appointment were much more likely than for any other service.

More than half (56%) of patients said they had been included in decisions about their care and treatment, while a little less than a fifth (18%) said they had not been. We also asked if patients were given the information, they needed to care for themselves, or were able to find that easily. Nearly half (47%) agreed with this statement and a quarter (26%) disagreed. This means a significant number of patients were left without the information they needed to care for themselves.

The most common negative impacts were on mental health and being unable to perform day-today tasks such as leaving the house, selected by more than half (53%) of respondents. Just under half (47%) said their health and care needs make them feel lonely or isolated. There was a negative impact on relationships with family and friends for 2 out of 5 (40%) people.

# **Useful resources**



## **Support for carers**

Carers have a fundamental role in the lives of patients living with a heart condition and their contribution is invaluable to patients' wellbeing. Here are some sources of advice and support:

- <u>NHS: Introduction to care and support</u>
- <u>Carers Trust</u>

## **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:

- <u>NHS talking therapies</u>
- <u>Samaritans</u>
- <u>Mind</u>
- <u>British Heart Foundation: Heart matters</u> <u>magazine – Mental Health, coping with</u> <u>anxiety and depression</u>

## Shared decision making

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 consider 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'.

- <u>NHS England: Shared decision making</u>
- <u>National Institute for Health and Care</u> <u>Excellence (NICE): Shared decision making</u>

## Learn CPR

St John Ambulance provides instruction on CPR on an <u>adult</u> and <u>child</u>.

# Where is my nearest public defibrillator (AED)?

The Circuit is the national defibrillator network which maps defibrillators across the UK, providing NHS ambulance services with vital information so that in those crucial moments after a cardiac arrest, they can be accessed quickly to help save lives. The Circuit works in partnership with the British Heart Foundation (BHF), the Resuscitation Council UK and St John Ambulance. The <u>Defib</u> <u>finder</u> will show you defibrillators close by.

A defibrillator registered on The Circuit could make the difference between life and death. There are an estimated 100,000 defibrillators across the UK. However, tens of thousands of these are unknown to ambulance and emergency services. Once located and registered, emergency services can direct bystanders to their nearest defibrillator and increase a person's chance of survival.

Since the launch, <u>The Circuit</u> has helped map over 50,000 defibrillators in the UK. Find out more and how to register your defibrillator.

Another option is the <u>HeartSafe website</u>, which has a map of defibrillators in the UK.

# What can I do to keep my heart healthy?

The British Health Foundation (BHF) Heart Matters magazine is a comprehensive and engaging resource for healthy lifestyle tips and personal stories about living with heart conditions. You can subscribe via the BHF website.

The <u>NHS Live Well</u> page offers advice about healthy living, including eating a balanced diet, healthy weight, exercise, quitting smoking and drinking less alcohol.

# Guide to useful apps for managing your heart health

We live in an increasingly online world. Smartphone and other online apps can help us navigate the bewildering amount of online support and advice out there. This guide is not meant to be prescriptive; it is intended to give you ideas about how you can use free online tools to help keep your heart healthy or manage an existing condition. In addition to the free apps suggested, you may be eligible in your local area for a range of digital health monitoring programmes involving home self-testing tools such as electronic blood pressure cuffs, or there are paid options for managing cardiac rehabilitation at home. Please consult your doctor before starting a new exercise regime or changing your diet.

For more details, we published a useful guide in 2020 to the many apps available to help you live with a heart condition or improve your health. This can be found **here**.

# Thanks and acknowledgements



This report was written by Richard Corder as a patient co-writer, and Sarah Colston, with support from the NCAP team and the NICOR Patient Representative Group chaired by Sarah Murray, with graphic design by NHS Arden and GEM CSU's Creative, Campaigns and Digital team.



## National Institute of Cardiovascular Outcomes Research (NICOR)

NICOR is a partnership of clinicians, IT experts, statisticians, academics and managers who are responsible for the National Cardiac Audit Programme (NCAP) and several health technology registries, including the UK TAVI registry. Hosted by Arden & GEM CSU, NICOR collects, analyses and interprets vital cardiovascular data into relevant and meaningful information to promote sustainable improvements in patient well-being, safety and outcomes. NICOR is funded by NHS England and the GIG Cymru (NHS Wales).

Email: nicor.auditenquiries@nhs.net



## **NHS Arden and GEM**

NHS Arden & GEM is a Commissioning Support Unit (CSU) working across England's health and care sector to provide a range of services, including procurement and contracting, service transformation, business intelligence, business support and clinical support. Its ability to draw upon expertise from over 1000 staff working in multidisciplinary teams enables the CSU to help healthcare commissioners and providers navigate and implement the change needed to improve patient care and outcomes. Arden & GEM's clients include more than 70 customers, including Integrated Care Boards, NHS England, Integrated Care Systems, Primary Care Networks, NHS provider trusts and local authorities.

www.ardengemcsu.nhs.uk



## **NHS England**

NHS England leads the National Health Service (NHS) in England. NHS England provides national leadership for the NHS. Through the <u>NHS Long Term Plan</u>, we promote high-quality health and care for all and support NHS organisations to work in partnership to deliver better outcomes for our patients and communities at the best possible value for taxpayers and to continuously improve the NHS. We are working to make the NHS an employer of excellence and to enable NHS patients to benefit from worldleading research, innovation and technology.



## **GIG Cymru (NHS Wales)**

NHS Wales is the publicly funded National Health Service of Wales, providing healthcare to some 3 million people living there. The Welsh Government sets the Health Care strategy, and NHS in Wales delivers that strategy and services via the seven Local Health Boards, three NHS Trusts and two Special Health Authorities. The NHS has a key principle: good healthcare should be available to all.

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## National Cardiac Audit Programme



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