



Whole Hearted

Working together
to save lives



Introduction by Trudie Lobban MBE Founder & CEO, Arrhythmia Alliance

Despite great recent progress in tackling cardiovascular disease by the NHS, the impact of heart disease's most deadly component has remained largely unchanged.

The 2004 National Service Framework (NSF) for coronary heart disease provided pivotal focus, contributing to a decade-long decline in cardiovascular deaths. The NSF provided the priority and the resources for components of the NHS to work as one to reduce cardiovascular deaths.

Despite this progress, the most deadly aspect of cardiovascular disease has remained largely unchanged. Cardiac arrhythmias were a late addition to the NSF, one that was unsupported by additional funding. Arrhythmias attract little NHS attention and are little understood by the public. Yet, an astonishing 100,000 still die each year because of sudden cardiac arrest (SCA) brought on by an arrhythmia. This number is virtually unchanged despite a halving in the number of deaths from cardiovascular heart attacks (myocardial infarctions) from 60,000 to 30,000 in the last decade.

Moreover, many of these deaths from SCA are preventable through the use of small medical devices that can shock the heart back to life in the event of a life-threatening arrhythmia. Yet in the UK we are providing many fewer of these than are needed. A recent high-profile case that highlights the need for preventative therapy was that of Bolton Wanderers footballer, Fabrice Muamba, who suffered a cardiac arrest and survived following a timely combination of defibrillation and CPR. Fabrice now has an implant that is on constant and automatic standby to correct an errant heart rhythm.

The UK lags behind almost every other European country in the use of this life-saving treatment, failing to achieve even the minimum numbers that cardiac specialists have calculated that we need. Compounding this overall neglect of patients at risk of SCA, huge regional differences exist across the UK. Patient access to heart-saving treatment is heavily postcode dependent.

Following the recent publication of the Government's Cardiovascular Disease Outcomes Strategy, it is essential that we continue to examine how to target and treat arrhythmias and, specifically, how to reduce the annual UK tally of deaths from sudden cardiac arrest. We now need to work together to ensure the strategy is implemented so that services and patient outcomes are improved. Despite widespread inequalities in the provision of treatment for arrhythmias, there are some areas of exceptional best practice to share and learn from across the NHS. It is our hope that the Whole Hearted campaign will help to raise awareness of the widespread inequalities of care across the country, including the quality of care people deserve, and ultimately help to prevent needless deaths from cardiac arrhythmias.

Trudie Lobban MBE

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INTRODUCTION

Working together to save lives



whole hearted

Arrhythmia Alliance's Whole Hearted campaign aims to make life better for those living with heart rhythm disorders. Each year an estimated 100,000 people die in the UK due to a sudden cardiac arrest.

Many of these deaths are preventable.

Yet despite this knowledge, the UK lags behind all other leading European countries in the numbers it treats with this life-saving technology. We aim to change that.

Cardiac arrhythmia

A cardiac arrhythmia is an abnormal heart rhythm often characterised by a heartbeat that is irregular, too fast or too slow.

These problems arise because of faults with the complex electrical system that synchronises the beating of the heart. Arrhythmias can occur at any age. Some are barely perceptible, whereas others can be more dramatic leading to stroke, heart failure, sudden cardiac arrest and death.

In the UK around a million people are diagnosed with an arrhythmia.

Typical arrhythmia symptoms include:

Palpitations, blackouts, breathlessness, fatigue and chest pain.

The consequences of arrhythmias include:

Cardiac arrest, sudden death, stroke and heart failure.

What is sudden cardiac arrest?

Each year an estimated 100,000 people die in the UK as a result of sudden cardiac arrest. The majority of these are due to rapid unstable heart rhythms called ventricular fibrillation.

The risk of SCA increases in the presence of damage to the heart such as that resulting from a heart attack. However, many patients are at risk of death due to electrical abnormalities independent of cardiovascular health. These abnormalities can sometimes be predicted by family history and include conditions such as long QT syndrome and Brugada syndrome.

BACKGROUND

Cardiovascular diseases (CVD) affect the heart and circulatory system and constitute the UK's biggest cause of death. It is estimated that CVD is responsible for around one in three premature deaths in men and one in five premature deaths in women.

The single biggest killer among these diseases is sudden cardiac arrest that kills 100,000 every year.

Over the past ten years there has been a sustained Government focus. However, heart rhythm disorders, such as those that cause sudden cardiac arrest, have attracted less public profile.

Specific national CVD initiatives over this time have included:

- **National Service Framework for Coronary Heart Disease – Chapter 8 (2005)**

Chapter 8 – Arrhythmias and Sudden Cardiac Death, included three quality requirements including:

Patient support – People with arrhythmias receive timely and high quality support and information based on an assessment of their needs.

Diagnosis and treatment – People with arrhythmias receive timely assessment by an appropriate clinician to ensure accurate diagnosis and effective treatment and rehabilitation.

Sudden Cardiac Death – NHS services should have systems in place to identify family members at risk and provide rapid access to services for those who experience symptoms predictive of sudden cardiac death.

- **National Institute for Health and Clinical Excellence (NICE) guidance on Implantable Cardioverter Defibrillators for Arrhythmias (2006)**

Extended provision of ICDs for primary prevention of sudden cardiac arrest including for those who have:

- Had a heart attack more than four weeks previously, have a severely damaged heart, and slow electrical activation of heart muscles

CASE STUDY:

Joanne Brookes, 30 years old, Middlesex

Joanne recently found out that she had a genetic heart rhythm disorder, and for several weeks was experiencing an abnormally fast heartbeat. During the same time period her sister had a sudden cardiac arrest. Joanne and her sister were subsequently both fitted with an ICD on the NHS. Only six weeks after the implant, Joanne returned to a normal, active working life.



“The ICD has enabled me to continue to do the things I love, such as play sports and lead an active life style, without it, I would be a different person.”

- Certain familial cardiac conditions including long QT syndrome and hypertrophic cardiomyopathy
- Undergone surgical repair of certain types of congenital heart disease

- **Heart Rhythm UK position statement on clinical indications for ICDs in adult patients with familial cardiac death syndrome (2010)**

Clinically led guidance which focused on the use of ICDs as an important potential means of preventing sudden deaths for those with genetic conditions including long QT syndrome, Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia, hypertrophic cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy.

- **Heart Rhythm UK Standards for Implantation and Follow-up of Cardiac Rhythm Management Devices (2011)**

A template for developing best practice in delivering safe, high-quality cardiac device therapy including staffing, training and electrophysiology requirements.

- **Cardiovascular Disease Outcomes Strategy (2013)**

Produced by the Department of Health and aims to provide advice to local authorities and NHS commissioners and providers about actions to improve cardiovascular disease outcomes. Identified ten key actions to improve outcomes including a focus on tackling sudden cardiac death and the provision of AEDs in the community.

Arrhythmia Alliance has responded to the NHS Commissioning Board's recent consultation on specialised services commissioning for ICDs; and the final report outlining the new arrangements for specialised clinical commissioning is expected to be published in spring 2013. We are calling on the Government to ensure the NHS implements the new commissioning guidelines as soon as possible to ensure all those at risk are given the right treatment.

CASE STUDY:

Lionel Levine, 63 years old, Essex

Lionel and his wife Susan were on a flight back from a holiday in Lanzarote on April 3rd 2012 when Mr Levine suffered a sudden cardiac arrest. His heart stopped three times on board and cabin crew and a doctor performed CPR and used an AED to keep him alive. The aeroplane was rerouted and stopped in Faro, Portugal where Mr Levine spent four days in intensive care. He eventually regained consciousness and was flown back to the UK about a week later. In May this year, on the recommendation of his consultant, he was fitted with an ICD. He is now on the road to a full recovery.



“Obviously once this happens at first you are worried something could happen again, but when I saw my cardiologist I understood the procedure for fitting an ICD and the device and I was completely reassured.”

ICD USE

ICDs have been proven to be cost-effective in reducing mortality and morbidity in patients with cardiac arrhythmias. Tens of thousands of ICDs are implanted each year.

CASE STUDY:

Mark Wendruff, 64 years old, Middlesex

Mark is a sudden cardiac arrest survivor. Following the support of CPR and an AED, he was fitted with an ICD in January 1995. Following that Mark arrested 2 times in the first few months of the implant being fitted – both times the ICD shocked him and re-started his heart. The first arrest happened on the street only 5-6 weeks after the implant, the second within 2 months of that. Since that first year he arrested again in 1999. So, in the span of 4 years there were three confirmed episodes where he arrested, his heart stopped and the ICD shocked him and re-started his heart – saving his life each time.

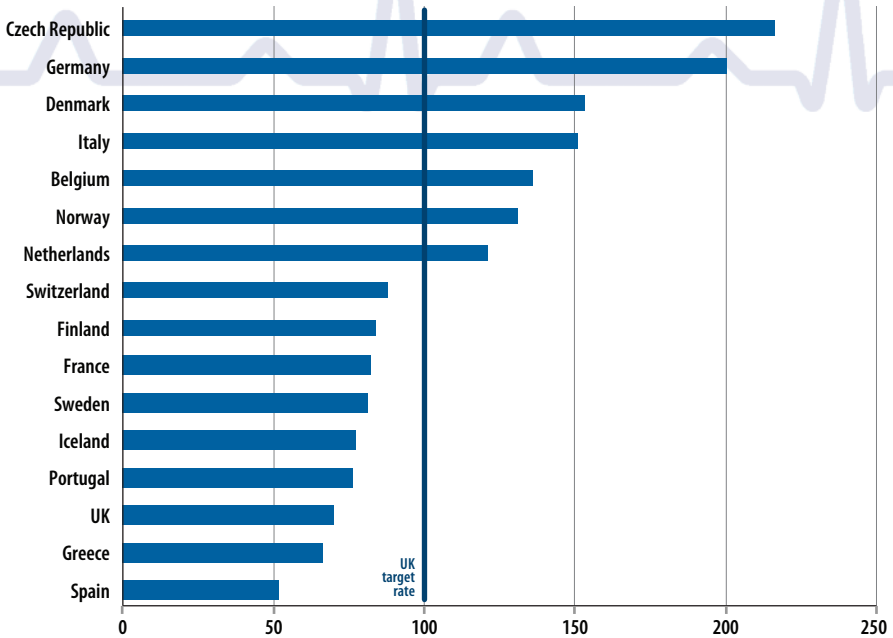


“If ICDs did not exist I would be dead.”

ICDs have been in use across western Europe for many years now. As technology has improved so has clinical and public awareness of the benefits of technology in this area. The following graphs show the figures from the 2012 Cardiac Rhythm Management UK National Clinical Audit Report.

The following table shows, despite the focus on tackling cardiovascular disease, that the UK still lags near the bottom of the league table in terms of ICD implants. In the UK we implant nearly under a third of the ICDs in Germany (per million population). The rate of ICD implantations in the UK is only 70 per million people, despite ambitions to double the rate of ICD implants in the UK from 50 to 100 per million people.

Figure 1. ICD Implant Rate – Western Europe



Source: NICOR Cardiac Rhythm Management UK National Clinical Audit Report 2012

ICD

A small implantable device capable of recognising rapid arrhythmias (ventricular tachycardia) when they occur, and, if necessary, delivering a life-saving shock to restore a normal rhythm. ICDs are placed below the collarbone by cardiologists specialising in electrophysiology. They are made up of a pulse generator, containing a battery and circuitry, and sophisticated leads that connect the generator to the heart.

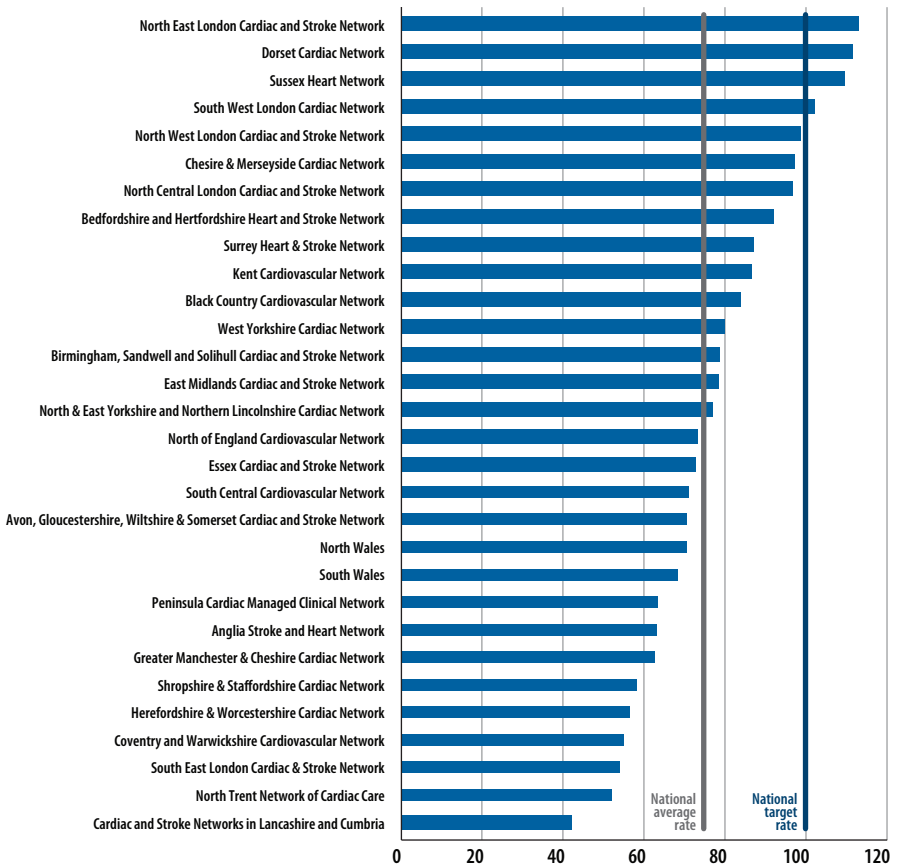
ICD USE

Continued

Equally worrying is the wide variation in ICD implantation rates across the UK, as the following graph shows. This illustrates that the chance of receiving an ICD implant varies dramatically according to where you live.

Patients in some areas such as Lancashire and Cumbria are less than half as likely to receive an ICD implant as those in high-performing network areas including many of the London networks.

Figure 2. ICD Implant Rate – England and Wales (adjusted for age and sex)



Source: NICOR Cardiac Rhythm Management UK National Clinical Audit Report 2012

CLINICAL VIEW

Professor Richard Schilling, Consultant Cardiologist, St Bartholomew's and Royal London Hospital

Figures from the ambulance services of the UK make it clear that there are huge variations in the survival after cardiac arrest across the country and the world.

Cardiac arrest needs to be distinguished from a heart attack (or myocardial infarction), which is only one of the causes of the heart developing a potentially fatal rhythm and stopping beating. Cardiac arrest can affect anyone although the average age of victims is 66.

The London Ambulance Service believe that survival rates are good in London not just because of the fantastic service that they provide but also because of the high level of bystander involvement when a victim suffers cardiac arrest. This is borne out by the experience of Seattle where a concerted public information and training programme has resulted in a survival rate of around 40-50% after cardiac arrest. London compares very favourably at 31.7% but the survival rate varies from 10 to 24% in other areas of the country.

After people have been identified as being at risk of cardiac arrest or even survived one, the UK still fails to match the rest of the world in protecting them with an ICD. We have an approximate understanding of how easy it is for patients to access this therapy by comparing our rates of ICD implantation with other similar countries and the UK continues to have lower rates of implantation than almost all European countries. The UK does have lower numbers of specialists than many other developed countries and this may be one of the reasons for this. Nevertheless the benefits of an ICD are clear and widely known so it is therefore difficult to understand why patients continue to not be told about this therapy and how it might benefit them.

Over the next five years the UK must change its focus to prevention of sudden cardiac death by increasing the rate of bystander resuscitation ideally with access to automatic external defibrillators and a concerted and focussed campaign to help those regions of the country who perform badly to appropriately prescribe ICDs.

How can we improve this?

At present in London around 40% of bystanders will attempt cardiac resuscitation with chest compressions. Even raising the rest of the country to this level could have a major impact on death rates.

WHAT WE ARE CALLING FOR

Arrhythmia Alliance will be working over the coming months to uncover specific blockages to treatment on the ground in the NHS. In the meantime we believe there should be:

- 1. A commitment by the Government to increase the rates of ICD implants to 100 per million people in the UK, and pacemaker provision to that of European average**
- 2. A new public awareness drive to ensure awareness levels of arrhythmias and sudden cardiac death reach those of vascular heart attacks**
- 3. Access to one-to-one specialist nursing care for all heart rhythm patients who require support**
- 4. Full implementation of NICE guidance on ICD implantation with regular reviews**
- 5. A review of UK implant centres in line with Heart Rhythm UK guidelines on training and staffing provision**
- 6. The development of a NICE Quality Standard on sudden cardiac arrest**
- 7. A commitment by the Government to increase the number of public access automated external defibrillators (AEDs) across the UK**

The Arrhythmia Alliance understands the need to make savings in the NHS but believes that there is a compelling case to reinvest money made from the £20 billion 'Nicholson' savings challenge in England to improve outcomes for those at risk of suffering sudden cardiac death.

CONCLUSION

The UK is seriously under-treating those patients with serious cardiovascular disease and who could benefit from an ICD.

There are likely to be many reasons for this including current funding pressures and a lack of public awareness of the condition.

Arrhythmia Alliance will be working through its Whole Hearted Campaign to uncover these reasons, push for real change on the ground and, in doing so, to help save lives.





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