Submission to the Cardiovascular Disease Outcomes Strategy
September 2012

1. We want to bring all CVD services up to the standard of the best. Are you aware of examples of good practice in cardiovascular service delivery that could be replicated?

Arrhythmia Alliance (A-A) supports the aim of levelling up CVD services to the standard of the best. In recent years the focus of health resources and government policy in the CVD area has been on myocardial infarction while heart rhythm disorders have not had traditionally the same level of attention. However, more than double the number who die from a vascular heart attack are killed each year by an arrhythmic cardiac arrest. Blackouts are one of the most common presentations to hospital, but often one of the most poorly managed. Up to 40% of patients with epilepsy are misdiagnosed each year in the UK and around 60% of these are found to have syncope. We would like to highlight areas of local good practice in delivering innovative care in the NHS in this area:

- **Manchester Heart Clinic based at Manchester Royal Infirmary**
  
  **Specialist-Nurse Led Rapid Access Blackouts Triage Clinic (RABTC)**

  The Heart Centre in Manchester is able to review all those who have collapsed due to a blackout/transient loss of consciousness (T-LOC). Each patient is referred by a GP or A&E department and they complete an online questionnaire with the specialist nurse upon arrival at the RABTC. Ultimately this data can be accessed by RABTC staff as well as the specialist to whom the patient is referred.

  The service provides a fast triage (aimed to be within two weeks) and a structured clinical assessment involving a 12-lead ECG. It is a specialist nurse led clinic involving those working in falls, arrhythmias and epilepsy. A cardiologist is also available to perform and interpret tests if and as appropriate. Total clinic time (four hours) is split into hours 1-3 where specialist nurses work to assess patients using data from online questionnaires and
Promoting better understanding, diagnosis, treatment and quality of life for individuals suffering with cardiac arrhythmia
cardiology and neurology investigations are performed and interpreted. During the final hour all clinic staff meet
to discuss cases and decide upon a preliminary diagnosis and referral.

- Specialist nursing services – cardiac rhythm management
  
  Nurse led arrhythmia clinics such as those at the John Radcliffe Hospital in Oxford provide crucial support for
  patients with a variety of arrhythmias. As well as providing specialist care they also help with improved patient
  information and education and act as a link with primary care health professionals. Arrhythmia nurses also
  participate in local and national education programmes for healthcare professionals. Specialist nurses also assess
  and prepare patients for complex procedures. Nurses also deliver telephone consultations and having a single
  individual who provides care throughout the patient pathway has been shown to be of immeasurable value.

2. What action is needed to reduce the number of people dying prematurely from CVD?

While there has been a downward trend in deaths from vascular heart attack in recent years, deaths from heart
rhythm disorders are rising. Deaths from sudden cardiac arrest currently claim around 100,000 lives in the UK each
year. A-A believes that there is a set of actions needed to reduce the number of people dying prematurely from
sudden cardiac death:

2.1 Improving access to Implantable Cardiac Defibrillators (ICD’s) & Pacemakers – the UK currently lags far behind in
the league table against other European countries (see Q.6) suggesting that we are undertreating patients with
medical devices that could save thousands of lives. There are complex reasons for this including awareness (by
patients and healthcare professions) and access to services, which warrant further investigation. It has been shown
that most people who die from sudden cardiac arrest do not have evidence of a fresh myocardial infarction. Rather,
evidence of old myocardial scarring is present. This indicates that such patients could have been risk-assessed
according to NICE criteria, and prescribed an ICD, and perhaps many lives would then be saved.

2.2 Public awareness of the risk of sudden cardiac arrest is low – despite recent high profile cases, for example the
footballer Fabrice Muamba who was treated successfully, there has been little in the way of a Government led public
awareness campaign for this important disease area.

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2.3 Healthcare professional awareness – there is a lack of standardised training for healthcare professionals in the diagnosis of heart rhythm disorders including for example, in interpreting ECG results. It is well documented that a significant proportion of syncope sufferers are misdiagnosed with epilepsy. This can have catastrophic consequences.

2.4 Detection of AF in Primary Care and pulse checks – there is currently no mandatory pulse checking in the NHS, despite the fact that a key way to find out if someone potentially has a heart rhythm disorder is to assess their pulse. Unfortunately, although new QOF Indicators for AF were introduced this year, they still do not reward GPs for discovering more cases of AF, only for anticoagulating those that they know of. In England the average number of known AF cases per practice is 80, but the range is 1-600. At least 80 more cases per practice exist to be diagnosed, and this requires a national programme and incentives. A-A believes that, at a minimum, pulse checking should form a key element in GP appointments, although this tends to find only one genuine case of AF for every five pulses that seem to be irregular, so many unnecessary ECGs need to be done. A national programme would encourage appropriate ECG testing in primary care. Opportunistic settings should also be utilised such as in pharmacies, community centres and schools. Education is also important to encourage self-delivery by individuals. Children of school age could be encouraged to be aware of pulse rates for example in their first aid training lessons.

2.5 Automated External Defibrillators – A sudden cardiac arrest victim treated with CPR and a defibrillator is ten times more likely to survive compared with someone who received CPR alone. It is therefore crucial that the NHS works with local authorities to increase the number of public access defibrillators and all first aid training includes CPR and defibrillator skills. This is not a wistful wish. In many other countries in Europe and Scandinavia such educational programmes have existed for years.

3. What more needs to be done to improve patients and carer experiences of treatment and care?

Specialist nurses provide essential one-to-one care through the patient pathway and beyond, acting as an advocate for patients. However, there is evidence that as the NHS in England works to deliver £20 billion of savings, specialist nurses are either not being replaced as they leave the service or are returning to general duties, and this vital link to the heart rhythm patient is being lost. Specialist nursing provision is in any case variable throughout the UK and we...
believe there should be greater prioritisation of this crucial service and a guarantee of one-to-one specialist nursing care for all those heart rhythm patients who need it. There is a particular need in the hospital sector for more specialist nurses to staff blackouts clinics and AF clinics. In these clinics it has been shown that many new patients with specific problems can be seen by nurses (with a doctor available if needed) and managed according to agreed protocols. This helps to reduce the misdiagnosis of epilepsy in blackout patients, and the risk of stroke in AF patients.

Patients should be informed and fully involved in their care decisions. There is a need for greater provision of information around heart rhythm disorders, for example via patient information leaflets illustrating the background to their conditions. Equally, as new technologies become adopted it is important that patients are provided with the right information, for example on ICD use.

4. **Bearing in mind there are no resources available to deliver this outcomes strategy, what do you think is the best way of delivering the proposals you have made for improving CVD outcomes?**

Money should be invested in common arrhythmia presentations and conditions where it can be shown or inferred that beds and money can be saved. The blackouts clinic at Manchester Royal Infirmary reduces readmission rates by two thirds. The model has been duplicated in Middlesbrough and a number of other UK centres. In Middlesbrough they were able to undertake a health economics impact study on their first 250 patients. This showed that a Rapid Access Blackouts Triage Clinic saves about £1,000 in the care-pathway of a blackouts patient. These data were presented to the local commissioners. The Middlesbrough clinic now has six full-time dedicated blackouts specialist nurses.

A-A has repeatedly highlighted low cost activities that can make a difference to people’s lives, for example through opportunistic pulse checks. However, with around 100,000 deaths each year from sudden cardiac death we believe this is an area where there is a strong argument for NHS investment where the returns are felt immediately in terms of patient outcomes. There is a compelling case to be made that of the £20 billion currently being saved in England a certain percentage should be made available for reinvestment into arrhythmia services to ensure that specialist nursing services continue and that everyone who could benefit from an ICD gets access to this treatment.

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5. Do you know any developments in prevention, diagnosis, treatment or management that will impact on the way in which CVD services need to be commissioning or delivered over the next decade?

Rapid Access Blackouts Triage Clinics can make a huge difference to the outcomes and costs of this very common presentation to UK hospitals, and they should be rolled out across the NHS sector.

A programme of effective opportunistic screening for AF in primary care could prevent thousands of strokes every year and hundreds of millions of pounds in stroke care.

New technologies are being developed in the field of ICDs, which have the potential to improve patient care experiences as well as outcomes. S-ICDs (subcutaneous implantable cardioverter defibrillators) are being developed which are less invasive than traditional ICDs. The risk of complications developing from these devices is likely to be lessened as they are implanted just under the skin without wires connecting directly to the heart.

6. As we work to improve CVD outcomes, what do you think are the main inequalities and how can we make sure that we continue to try and tackle them?

There is huge inequality in the area of heart rhythm disorder management. Recent data from the Cardiac Rhythm Management UK National Clinical Audit 2010 shows the UK falling well behind European implant rates for ICDs (both new and replacement). In fact the UK ranks third from bottom, ahead of Portugal and Spain, but well behind leading countries including Germany and the Netherlands. Whereas countries at the top of the table have implant rates of up to 300 ICDs per million inhabitants, the rate in the UK is in the range of 60 – 100 per million. Not only does this signify that the NHS is falling well behind other Western European countries but also that patients in the UK are being under treated with these life saving implant devices.

The same study looks at the rate of new implants across the UK compared to the national target (100 new implants per million of population), by cardiac network population. Almost every network falls below target with the overwhelming majority below the lower control limit and therefore significantly below the national target. Within these networks however is a significant variation meaning that a patient’s chance of receiving a potentially life-
Promoting better understanding, diagnosis, treatment and quality of life for individuals suffering with cardiac arrhythmia-saving implant is subject to a postcode lottery. A-A is committed to carrying out further research as why there is such inequitable provision in the UK. At the same time, UK government policy on the NHS has focussed almost exclusively on coronary heart disease and some of its consequences such as heart failure. Whilst an elevated cholesterol is taken very seriously, an elevated heart rate with irregular rhythm is not a government target, and is often ignored.

7. Any other comments?

A key element of the CVD outcomes strategy should be about levelling up standards to the very best and taking a broad view of the disease area. In A-A’s view this includes increasing access to a variety of treatments and devices including ICDs, and reducing the variability of provision throughout the UK. An urgent reprioritisation of heart rhythm disorders is needed so that there is a renewed focus on levelling up standards to levels seen in comparable Western European countries. A-A understands that there is no new funding to sit alongside this outcomes strategy. However we believe that efficiency savings could be usefully redirected to this area, ultimately potentially saving the NHS more money in the long-term as well as saving lives and improving patient experiences of care. We can demonstrate that blackout clinics reduce re-admissions, as well as the human and financial cost of a misdiagnosis of epilepsy, thought to cost at least £200m in the UK. We can demonstrate that opportunistic screening for AF in primary care is cost-effective, and even a mildly successful programme will save money and many strokes.

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