

DATA COLLECTION AND AUDIT OF ARRHYTHMIAS IN THE UK

KEY POINTS:

1. Audit in arrhythmia management is currently inadequate (with the exception of the National Pacemaker & ICD Database).
2. Accurate data collection is essential to allow development of an equitable service for arrhythmia patients.
3. Implementation of a national electrophysiology/catheter ablation database is critically important, and will require close collaboration between interested parties.
4. Linkage with the existing databases in CCAD is vital.
5. Audit of anticoagulation in patients with atrial fibrillation is important, as opportunities to reduce the risk of stroke are being missed.
6. Implementation of effective data collection will require extra resource.
7. Databases, information handling and audit require a national strategy, and web-browser based systems need to be developed for ease of access.

INTRODUCTION

Unfortunately, the number of patients presenting with arrhythmias is unknown, and therefore the need for provision of arrhythmia services is difficult to predict. Catheter ablation numbers have recently been compiled using HES (Hospital Episode Statistics), and made available by personal communication, although there is doubt about their reliability and completeness. The returns suggest that the availability of catheter ablation is only one tenth of that in some parts of Western Europe and the USA. The numbers of patients presenting with blackouts/T-LOC who are satisfactorily diagnosed and rendered asymptomatic is unclear, although both arrhythmias and blackouts consistently appear amongst the 10 commonest reasons for non-elective hospital admission. The National Pacemaker and ICD Database¹ has collected data relating to pacemaker and ICD implantation over the past 20 years. This database is relatively complete, and much effort has been expended in validating it. It has allowed comparison of pacemaker and ICD implantation rates in the UK with those particularly in Western Europe, and has demonstrated a marked shortfall in device implantation in the UK compared with comparable European countries. Unfortunately, however, this database has not been exploited to its maximum effect nationally. Locally, it and related databases, have allowed audit of device implantation, which has been useful in the assessment of performance.

WHY IS INFORMATION SO SCARCE?

The reasons are many, but probably include:

- Lack of an audit culture (despite the success of the pacemaker database).
- Lack of resources for clinical databases.
- Lack of time apportioned for data collection, review of results and audit.
- Lack of support staff for clinicians.
- Lack of communication between primary, secondary and tertiary care.

There are no systems in place to encourage accurate and timely data collection in arrhythmia management in the UK. The National Service Framework in coronary heart disease has required audit data relating to cardiac procedures (percutaneous coronary intervention and coronary artery bypass graft surgery), to diseases and conditions (heart failure) and to treatments (door to needle time) etc. It will also therefore be able to provide encouragement to collect audit data for the management of patients with arrhythmias.

Lack of resource is particularly important. As information technology is improving in the NHS, lack of hardware will become less of a problem, but lack of staff remains important, both locally, where the data will be collected, and centrally, where they should be analysed.

CURRENTLY AVAILABLE DATABASES

There already are a number of databases either in use, available, or proposed. These include

1. National Pacemaker and ICD Database, to which data are contributed by almost all pacing centres in the UK

¹ National Pacemaker and ICD Database, PO Box 9205, Bridge of Weir, Strathclyde, PA11 3DZ, mwc@btconnect.com

2. National Electrophysiology Database,² which has not been widely implemented so far
3. Cardiology Audit and Registration Data Standards (CARDS)³
4. Various local (usually electrophysiology) databases

PROPOSALS FOR STANDARDS FOR DATA COLLECTION AND AUDIT

Current and new databases should be compatible with data already collected by CCAD. The importance of this has been shown by linkage of the ICD database and MINAP,⁴ which has given important information about the shortfall in ICD implantation in the UK.

PROCEDURES

Collection of data relating to procedures is probably relatively easy to implement

PACEMAKERS & ICDS

Pacemaker and ICD data are already collected, via the National Pacemaker and ICD Database, now in conjunction with CCAD

ELECTROPHYSIOLOGY & PERCUTANEOUS CATHETER ABLATION

A national electrophysiology/radio frequency ablation database has been established through CCAD, but despite attempts to encourage its implementation, data are only being submitted from a minority of electrophysiology laboratories. It is most important that this (or a similar) database, compatible with CCAD be implemented, so that the numbers of patients undergoing catheter ablation can be determined, along with the success and complications of the procedures. It is proposed that a committee comprising those with particular interests in developing clinical databases from CCAD, UKICES & BPEG refine the existing national database, which could then be rolled out with the NSF. Ablation of atrial fibrillation is an important new therapy in evolution. It is particularly important that its success and complications be monitored, and this may merit a separate linked database to allow sufficient detail to be collected. Standards have been proposed by the ACC/AHA.⁵

PARTICULAR DISEASES & CONDITIONS

Certain diseases and conditions merit audit of their management.

ATRIAL FIBRILLATION

Consideration of anticoagulation in patients with atrial fibrillation is important, as the risks of stroke associated with AF can be very significantly reduced by anticoagulation with warfarin. Atrial fibrillation and its management could be monitored via the coronary heart disease register in primary care.

² designed and implemented by BPEG, through CCAD

³ The CARDS Expert Committee for Clinical Electrophysiology, (John Camm, personal communication)

⁴ Cunningham et al, Heart Rhythm 2004;1 (May supplement):S58

⁵ McNamara et al, Circulation 2004;109:3223-3243.

SUDDEN DEATH SURVIVORS

The management of those resuscitated out of hospital is often suboptimal.⁶ Some of these failures will have been addressed by the current NSF (eg beta blocker, statin and ACE inhibitor prescription), but others (eg coronary angiography, ICD implantation) have not been. Information is already collected about those resuscitated using public access defibrillators, but it is not clear if further information about their subsequent management is available.

HEART FAILURE & LBBB

Cardiac resynchronisation therapy is often very helpful in patients with symptomatic heart failure, left bundle branch block and systolic dysfunction. Left bundle branch block could be added to the coronary heart disease register in primary care, with encouragement to refer for consideration of CRT.

BLACKOUTS/T-LOC

Blackouts clinics should be audited, to include diagnoses and outcomes.

SUMMARY POINTS:

- whilst data-collection and audit in healthcare is difficult, time-consuming and complex, without good data activity levels cannot be assessed, access to care cannot be determined, and outcomes of care cannot be shown
- the NHS has a near monopoly of publicly provided healthcare in the UK and a major information initiative on-going through the National Programme for IT, (NpfiT), supported by significant new resources
- clinical databases have consistently been shown to fail if they are top-down and management driven, and consistently succeed if they are bottom-up and clinician driven
- clinicians involved in arrhythmia care must be motivated and engaged in data-collection to give an accurate idea of who is getting what treatments provided for them, with what measurable outcomes, and who is missing out on treatment
- trusts must support IT involvement for clinicians involved in arrhythmia care with time and money
- some clinicians may be able to contribute IT skills, others will need back-up with data-clerks at the point of service-delivery
- some National societies such as the British Cardiac Society and the British Cardiac Intervention Society have a laudable track record in data-collection, assimilation and presentation it is time that professionals involved in arrhythmia care followed this example
- **Databases, information handling and audit require a national strategy, and web-browser based systems need to be developed for ease of access**

⁶ Cobbe et al, BMJ 1996;312: 1633-1637.

CONCLUSIONS

Appropriate data collection and analysis are vital in order to ensure that an effective and equitable service is provided nationally to patients with or at risk of arrhythmias. It will require significant investments of time and money to ensure that it can be implemented.