Arrhythmia and SCD

Chapter 8 of the CHD National Service Framework – Arrhythmia and Sudden Cardiac Death

3 Quality requirements:

- **Patient Support** - **Aim**: to improve the emotional support offered to patients with arrhythmias and their families. **Quality requirement**: People with arrhythmias receive timely and high quality support and information, based on assessment of their needs

- **Diagnosis and Treatment** – **Aim**: To ensure expert assessment of a person in whom an arrhythmia is suspected, and that an appropriate and clinically effective care pathway is followed. **Quality requirement**: People presenting with arrhythmias, in both emergency and elective settings, receive timely assessment by an appropriate clinician to ensure accurate diagnosis and effective treatment and rehabilitation

- **Sudden Cardiac Death** – **Aim**: To reduce mortality from sudden death and improve services for families who have lost a close relative. **Quality requirement** – When sudden cardiac death occurs, NHS services have systems in place to identify family members at risk and provide personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives
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Roles and responsibilities

• **NHS, other specialists/professionals** – championing Ch8 and making it work
• **Cardiac Networks** – planning for delivery of Ch8; promoting joined-up working and cross-boundary engagement; assisting provider/commissioner discussions; supporting the local development of protocols; local target setting, monitoring and benchmarking
• **Heart Improvement Programme** – assisting the development of cardiac network capabilities; using local information to bring consistency of approach nationally; developing patient and public involvement
• **DH** – overall programme management; linking Ch8 and wider national programmes (NICE; workforce; PbR; PBC; audit and monitoring; etc.); working closely with HIP on issues that require (at least initially) a national focus
• **Patient organisations** – AA, CMA, CRY, SADS UK, STARS: raising awareness and service quality; promoting better support and care for patients, families and carers; working at a national level with DH, HIP to on appropriate policy development
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Roles and responsibilities – who should do what?

Key: a balance needs to be found to ensure effort isn’t duplicated and that best use is made of resources, expertise and local knowledge:

• What should the NHS and/or cardiac networks lead on (with HIP help and support)?

• Which issues need, at least initially, some national development work (DH/HIP)?

• What other national support work needs to be built on?

• Which issues should patient organisations be supported to take forward?
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3 current national focus areas (not just DH though)

Focus area 1: Joining-up services

Focus area 2: SCD and inherited cardiac conditions

Focus area 3: Provision of heart rhythm management devices
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2 wider themes for the future?

Theme 1: more engagement of primary care

Theme 2: more of an age-specific focus for Chapter 8
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Current national focus areas

Focus area 1: Joining-up services

Issue(s):
• Arrhythmia care co-ordination; developing the nursing role; rapid access clinics

Progress/developments/supporting work
• BHF funding for 26 arrhythmia care coordinators (ACCs); adoption of existing ACCs
• Evaluation of ACC role by University of York
• Chapter 8 Skills for Health competencies launched [22 June 2006]
• Arrhythmia, syncope, blackout services being developed
• Heart Rhythm UK Nurse and AP lead [Jayne Mudd]
• RCN Cardiovascular Nurses’ Network
• Establishment of National Arrhythmia Care Co-ordination Group
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Current national focus areas

Focus area 2: Sudden Cardiac Death (SCD) and Inherited Cardiac Conditions (ICC)

Issue(s):
- Better, coordinated support for families and carers, and the service
- Better data on incidence and cause
- Support guidance on risk and clinical management
- More consistency/appropriateness of ICC service development
- Developing the role of coroners and pathologists
- Support development of clinical genetics services and appropriate commissioning of genetic tests

Progress/developments
- CRY support for young sudden cardiac death services
- Establishment of National SCD/ICC Delivery Group and a Coroner/Pathologist National Interest Group,
- Development of a UK cardiac pathologist services
- HRUK, BCS work on risk and clinical management of ICC patients
- HIP/DH national Chapter 8 event on 21 November
- Development of a 'blueprint' for ICC services
Inherited cardiac condition identified

Communication

SCD → Coroner → Pathologist → Family/carer → GP

Gene testing

Bereavement and other general counselling

referral

Local ICC service

Specialist ICC clinic

What happens now (?)
Inherited cardiac condition identified

SCD → Coroner → Cardiac pathologist

National SCD Coordinating Centre [database of SCD cases and provision of family/carer information]

Information for family /carer

Empowered family/carer

GP

Bereavement and other general counselling

Preferred configuration (?)

Gene testing

Local ICC service

Specialist ICC clinic

Preferred configuration (?)

Notification

National support for cardiac pathologists
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Current national focus areas

Focus area 3: Provision of heart rhythm management devices (HRM-D)

Issue(s):
- UK rates well below Western European rates
- Inequity of access between cardiac networks and PCTs within networks
- Inconsistency in temporary pacing services
- Better national patient support and rehabilitation needed
- Remote device follow-up and new technologies
- Case to be made for commissioning these services

Progress/developments
- Establishment of National HRM-D Taskforce (with HRUK backing and involvement)
- National ICD/pacemaker mapping completed – 2005 data now being made available
- Most cardiac networks have their own report; others funding themselves
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Current national focus areas

*Focus area 3: Provision of heart rhythm management devices (HRM-D)*

National Heart Rhythm Management Device TF workstreams:

- Advice and support for commissioning
- Inequity of access
- National patient support
- Information and awareness raising – general
- Awareness raising, education and training, and service referral – primary and secondary/tertiary care
- Audit
- Rehabilitation
- Temporary pacing
- Remote monitoring/follow-up; new technologies
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Wider themes for the future

Theme 1: More engagement of primary care

Issue(s):
- General arrhythmia case identification and management; but particularly for AF
- Links with secondary and tertiary care services
- Involvement in inherited cardiac condition cases
- Making a commissioning case for treatment of AF

Progress/developments/supporting work
- 30 new QOF points for AF
- NICE AF guideline [28 June 2006]
- HIP national Chapter 8 event on primary care [11 July 2006]
- Cost-benefit analyses being carried out for AF
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Wider themes for the future

Theme 2: Age-specific services

[some of the] Issues:
• Promote primary prevention in the elderly
• Promote links between arrhythmia services, falls services and stroke services
• More engagement of primary care, general medicine and geriatric care in pacing/ICD services
• More appropriate services for young people (particularly those at risk of an inherited cardiac condition)

Progress/developments/supporting work
• Engagement of primary care and older people Tsars on pacing rates
• A&E paediatrician now on DH Chapter 8 Board
• Young sudden cardiac death now a national focus
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### Context

**Theme 2: Age-specific services**

- Atrial Fibrillation, affects up to 1% of the population, rising to 4% in the over 65s, and absorbs almost 1% of the entire NHS budget
- The overall incidence of stroke is about 5% per year in people with AF
- The majority of the approximately 100,000 sudden cardiac deaths each year in the UK are caused by CHD. However, most sudden cardiac deaths in people aged under 30 years old are caused by inherited cardiomyopathies and arrhythmias
- An estimated 400-500 cardiac deaths each year are unexplained and the majority of these have a genetic basis
First pacemaker implant rate vs age

Pacemakers

New Implant Rate 2005 (England)
First ICD implant rate versus Age

ICDs

The need for ICD implantation increases less with age, and begins to decrease after the age of 70. This is unlikely to be due to ageism, because the pattern is exactly the same in a number of other European countries. It is likely that the observed relationship reflects the different clinical aetiology of ICD patients.

There were 4,669 new ICD implants in 2004 and 2005, a mean annual new implant rate of xx.x per million population. The implant rate, on the Y axis, is NOT logarithmic. Implant rates in men are generally at least 5 times higher than in similarly aged women.
What proportion of the country’s TOTAL implants are in patients aged 75 and over?

Source: 2005 data from the UK, French and Belgian national registries

- England: ~58%
- France: ~69%
- Belgium: ~72%
What proportion of the country’s TOTAL implants are in patients aged 85 and over?

- England: ~17%
- France: ~21%
- Belgium: ~28%

Source: 2005 data from the UK, French and Belgian national registries
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Wider Key challenges

- Workforce, education and training issues
- Capital programme; development of catheter labs
- Ongoing NICE programme
- Ongoing QOF development
- Patient involvement
- 18 week waits (particularly diagnostics)
- Integration into wider DH policy initiatives
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If you want to get involved with any of these issues at a national level, please let me know:

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