

DH INFORMATION READER BOX

Policy	Estates
HR / Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working

Document Purpose	Consultation/Discussion
ROCR Ref:	Gateway Ref: 3241
Title	New NSF Chapter on Arrhythmias and Sudden Cardiac Death: A Consultation Paper
Author	Department of Health
Publication Date	12 May 2004
Target Audience	Voluntary/professional organisations
Circulation List	
Description	Consulation document for new NSF chapter on cardiac arrhythmias and sudden cardiac death
Cross Ref	n/a
Superceded Docs	n/a
Action Required	n/a
Timing	Deadline for responses: 4 August 2004
Contact Details	Jennifer Francis SHS-CHD 403 Wellington House 133-155 Waterloo Road London SE1 8UG 0207 972 4513 www.dh.gov.uk/consultations
For Recipients Use	

New NSF Chapter on Arrhythmias and Sudden Cardiac Death

A Consultation Paper

Introduction

- 1 The National Service Framework for Coronary Heart Disease, published in March 2000, heralded a new era for the development of fast and modern services for the prevention and treatment of heart disease. Four years on from its publication, the combination of a clear set of national standards, sustained levels of investment and reform and redesign of services has delivered real improvements for patients. Primary care has made extraordinary progress in ensuring that patients with heart disease are on the right combination of drugs to lengthen their lives. Waiting times for bypass surgery and angioplasty have fallen dramatically. Patients with a heart attack are treated quickly with life-saving clot busting drugs.
- 2 With significant progress now secured for patients with coronary artery disease, the NHS is now well placed to deliver similar improvements for patients with arrhythmia and with syndromes that can lead to sudden cardiac death. These patients have already benefited from the substantial growth in NHS staff, equipment and facilities. The Government has now agreed to drive further progress for these patients by working with patients, families and NHS professionals to develop new NSF standards or practice recommendations for these conditions.
- 3 The strength of the existing NSF has been that it is based on the views of clinicians, patients and their families. Its aims and approaches have credibility with those who deliver it and those who benefit from it. The aim of this consultation paper is to invite initial comments from everyone with an interest in these issues to

ensure that we can build a similar consensus for this new NSF chapter.

- 4 The views received will be considered by a new expert group which is being established by the Department of Health to take forward the task of writing the new NSF chapter. Detailed membership of the group will be published shortly, but it will include patients, relatives of patients, patient organisations, professional bodies, experts in the field, health service managers and other Government departments with an interest. The group will be chaired by Dr Roger Boyle, National Clinical Director for Heart Disease, and is aiming to produce the new chapter within 12 months.
- 5 The attached paper sets out the proposed scope of the work and how we propose to take the work forward. In addition to your comments on this way forward, we would welcome specific views on:
 - **Whether the scope covers all the aspects of these conditions which the new NSF chapter should cover;**
 - **Examples of existing good practice in the management of these conditions which might inform the work of the expert group;**
 - **Views on the obstacles to progress on developing state of the art services for these patients, and suggestions on how these might be overcome;**
 - **Areas where further research is needed to improve understanding of these conditions;**
 - **Views on what the immediate, medium term and long term priorities should be for these services; and**
 - **How best to ensure that the patient, family and carer perspective is at the forefront of policy and service development.**
- 6 Details of how to respond to this consultation are included at the end of this document.

Expert Group

Membership

The group will be composed of external stakeholders similar to the expert external reference groups who helped create the National Service Framework for Coronary Heart Disease with voluntary and professional organisations being invited to take part. Patients, cardiologists, GPs, nurses and members of voluntary and professional organisations (including CRY, the Ashley Jolly SAD Trust, Hearty Voices, the British Cardiac Society and the British Pacing and Electrophysiology Group) will be asked to join. Representatives from Wales, Scotland and Northern Ireland will also be invited.

Other Stakeholders

We will be holding a stakeholders' event during the consultation period to raise awareness of the new group and invite wider consultation and participation. This will help to ensure that the key issues are covered and that the outcomes address the needs of all the interested parties. If you would be interested in attending this event, please e-mail your name and contact details to jennifer.francis@doh.gsi.gov.uk.

Proposed Workstreams

We propose four key workstreams for the expert group to manage its work, Sudden Cardiac Death and Screening; Acute Care; Cardiac Interventions; and Patient Involvement and Support.

Sudden Cardiac Death and Screening

It is estimated that 200-400 young people die from sudden cardiac death syndrome each year. Dari Taylor MP's recent Private Members Bill highlighted a number of important issues which the new NSF Chapter will need to address. These include:

- Raising awareness of signs and symptoms of conditions which may lead to sudden cardiac death;
- Support for those who have lost relatives or friends;
- Considering the feasibility of guidelines on how these deaths are certified;
- Setting standards or practice recommendations around how suspected cases are treated in primary care;
- Promoting models of good practice for local use; and
- Design of an evidence-based protocol which clarifies when it is recommended that patients and/or their relatives should ideally be invited for screening.

Acute Care

For many patients the first sign of their cardiac condition is an emergency admission to hospital. Those who know they have the condition but whose care is not well managed may also need urgent treatment. Arrhythmia is consistently in the top 10 reasons for hospital admission, using up significant A&E time and bed days. This workstream will cover:

- Design of a care pathway showing the ideal treatment of those who require emergency care for these conditions;
- Outlining what information patients require when in hospital to help them successfully manage their condition after discharge;
- Considering the feasibility of setting or practice recommendations around readmission rates for those with conditions which could be better managed; and
- Development of a set of audit indicators and suitable performance indicators that might be used locally around emergency care for those with arrhythmias and conditions which may lead to sudden cardiac death.

Cardiac Interventions

Since publication of the NSF there have been significant improvements in both the technology and the clinical capacity to intervene to treat arrhythmias and related conditions, giving more options for this group of patients in terms of both diagnosis and treatment. New emerging technologies such as the implantable cardioverter defibrillator (ICD) or more sophisticated pacing devices, with good medical evidence for their use, has given the cardiologist many more treatment options in 2004 compared to the 1990s. This workstream will cover:

- Design of a care pathway for the diagnosis, management and treatment of arrhythmias and conditions which may lead to sudden cardiac death (considering cardiomyopathies, atrial fibrillation and electrical conduction disorders);
- Identification of models which deliver the appropriate interventions reliably; and
- Development of audit measures and suitable performance indicators around the care and treatment of people with these conditions, which might be used locally.

Patient Involvement and Support

Patients with a lifelong or long term cardiac problem need continuing support to help them manage their condition and live as full a life as possible. Assistance also needs to be available for carers and family members where they wish it. Patients need to be involved in decisions about their own care and in helping to shape the planning of services.

This workstream will include:

- Design of care pathway for management and control of specific conditions (for example, atrial fibrillation);
- Development of guidance on monitoring patients with chronic conditions;
- Identifying effective ways of providing emotional support to patients and their relatives where appropriate; and
- Identifying effective means of involving patients in their own care and in influencing the way that services are provided.

Next Steps

Ideas and proposals should reach the project team by **4 August 2004** at the latest.

The Department of Health would welcome contributions throughout the consultation. Emerging issues and contributions will be fed into the discussions of the expert group and used to develop the proposed new NSF chapter on arrhythmias and sudden cardiac death.

The information you send to us may need to be passed to colleagues within the Department of Health and/or published in a summary of responses to this consultation. We will assume that you are content for us to do this and, if you are replying by e-mail, that your consent overrides any confidentiality disclaimer that is generated by your organisation's IT system, unless you specifically include a request to the contrary in the main text of your submission to us.

Contact Details

New NSF Consultation
Heart Team
Department of Health
403 Wellington House
133-155 Waterloo Road
London SE1 8UG

Email: chdnsf@doh.gsi.gov.uk

Website: www.dh.gov.uk/consultations

Telephone: 0207 972 4513

Annex: Consultation Criteria

Code of Practice on Consultation

We will ensure that this consultation meets the following criteria:

1. Consult widely throughout the process, allowing a minimum of twelve weeks for written consultation at least once during the development of the policy.

2. Be clear about what your proposals are, who may be affected, what questions are being asked and the timescale for responses.

3. Ensure that your consultation is clear, concise and widely accessible.

4. Give feedback regarding the responses received and how the consultation process influenced the policy.

5. Monitor your department's effectiveness at consultation, including through the use of a designated consultation co-ordinator.

6. Ensure your consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment if appropriate.