INQUIRY INTO THE AUDITOR GENERAL FOR SCOTLAND (AGS) REPORT
“CARDIOLOGY SERVICES”

SUBMISSION FROM CHEST HEART & STROKE SCOTLAND

Introduction

Chest Heart & Stroke Scotland [CHSS] aims to improve the quality for life for people in Scotland affected by chest, heart and stroke illness, through medical research, influencing public policy, advice and information and support in the community.

CHSS welcomes the Public Audit Committee’s enquiry into NHS cardiology services in Scotland, and is grateful for the opportunity to contribute to the Committee’s review. We particularly welcome the Committee’s visit to CHSS patient support groups, which provides members with the opportunity to hear at first hand of patients’ experiences of diagnosis, acute treatment, rehabilitation and long-term support of people with heart disease in Scotland.

Overview

CHSS recognises the substantial progress which has been made in recent years in Scotland in the provision of cardiology services. Mortality rates have fallen significantly (albeit from a high base) and there have been major improvements in areas such as revascularisation services, cardiac rehabilitation and heart failure support. Waiting times have reduced very considerably, with consequent improvements in patients’ outcomes and quality of life. The Heart Disease and Stroke Action Plan sets clear priorities for further action.

However, as the Auditor General’s 2012 report makes clear, there are still areas where further progress is required, including:

- Ensuring equity of access to acute services across Scotland, both geographically and for people in more deprived areas
- Better co-ordination and widening of access to post-discharge services, particularly cardiac rehabilitation and heart failure support
- Further public health and health promotion measures to control risk factors and reduce the incidence of heart disease.

Heart disease remains one of the major threats to the health of the Scottish population, responsible for 8,000 deaths per annum, and with 235,000 people living with the impact of heart conditions.
CHSS contribution

Research

CHSS is one of Scotland’s largest charitable funders of research into the prevention, diagnosis, treatment and rehabilitation of heart disease. Over the past five years we have awarded more than £3.1 million in project grants, research fellowships and pilot studies in CHD alone, all raised from our fundraising activities with the Scottish public. Examples of current studies include:

- **TASCFORCE (Professor J Belch, Dundee)**
  - has screened more than 4,000 apparently healthy individuals across Tayside and Fife for early signs of cardiovascular disease, testing the effectiveness of a range of novel screening techniques, including MRI; has already generated significant benefits through early detection and treatment of heart disease, with consequent savings to the NHS

- **TOPCAT (Dr Richard Lyon, Edinburgh)**
  - has trialled therapeutic hypothermia and improved resuscitation for patients suffering out-of-hospital cardiac arrest in Lothian; with an associated training programme for paramedics, also funded by CHSS, has improved survival rates more than 3-fold; when rolled out across Scotland as planned, should save up to 300 lives a year

Influencing public policy

Working with colleagues in the NHS and other charities, we seek to promote the highest standards in patient care across Scotland, through, for example:

- Campaigning on national issues, including the Scottish Campaign for Cardiac Rehabilitation, aiming to improve equity of access to evidence-based care and support
- Raising community awareness of the signs and symptoms of heart problems and the appropriate action to save lives, in partnership with the Scottish Ambulance Service and BHF Scotland
- Supporting the work of professional groups such as the Scottish Heart Failure Nurse Forum and Cardiac Rehabilitation Interest Group Scotland, to promote education and development and thereby improve standards of care
- Represent the interests of patients and carers on the National Advisory Committee on Heart Disease and on managed clinical networks throughout Scotland
**Advice and information**

Through our Advice Line, publications programme and community-based nurses, we:

- Provide direct confidential advice and support to more than 2,000 patients, carers and professionals every year
- Send out nearly 200,000 easy to read booklets and factsheets on living with and understanding chest, heart and stroke conditions, including specific resources to empower patients and carers to get the most out of services e.g. *“How to make the most of a visit to your doctor”*
- Deliver health promotion talks and blood pressure screening to local community organisations and employers across Scotland

**Services in the community**

With staff and services based in local communities across Scotland we also:

- Support the rehabilitation of people following heart illness through our network of more than 50 affiliated cardiac support groups, with a total membership of over 2,500
- Tackle the social isolation caused by heart failure with our four established and innovative Heart Failure Support Services, providing volunteer befrienders, forum meetings and newsletter support
- Give welfare advice and support to the most vulnerable in society, through supporting benefits advisors in Citizens’ Advice Bureaux in Glasgow, Fife and Lanarkshire
- Provide personal support grants to those experiencing financial hardship, to maintain independence and enhance quality of life

**Voices Scotland**

Bringing all of these together is our innovative patient involvement work, **Voices Scotland** “**supporting you to have your say; patients, carers and staff working together to improve NHS services**”. For seven years, the Voices Scotland programme, delivered by CHSS, has built a national network of over 500 people affected by chest, heart and stroke conditions to help them have their say. Through Hearty Voices Scotland, Chest Voices and Stroke Voices workshops and ongoing support, patients and carers from all walks of life have been provided with the knowledge, skills and confidence to work with the NHS to help plan new and better services.
A patient view

In preparation for the meeting of the Committee, CHSS has undertaken a questionnaire survey of members of affiliated cardiac support groups throughout Scotland. The aim of this survey is to identify patients’ experiences of their condition, when and why they first sought help, their experiences of NHS services, and any perceived barriers to access to these services. In light of the findings of the Auditor General’s report, and the Committee’s concerns, we were particularly interested in any differences between respondents in terms of gender, urban-rural location, and levels of social deprivation (there were insufficient numbers to analyse by ethnicity).

The survey is still underway and, if requested, will be reported in full to the Committee at a later date. To date, responses have been received from members of groups ranging from Orkney to inner-city Glasgow, and analysis of the first 100 returns reveals the following preliminary findings:

- Males were more than twice as likely as females to seek help for the first time following an incident of sudden acute pain
- Conversely, women seemed much more likely to turn to NHS services as a result of a gradual deterioration of their health and the longer-term impact on their quality of life than men
- The same pattern is evident in how NHS services were accessed. More than twice as many men than women contacted what might be termed ‘emergency’ services – dialling 999, going directly to an A&E Department, or calling NHS 24 – and did so on the day they first became aware of any symptoms
- In contrast, 9 out of 10 women (compared to half of men) first contacted their GP, and only 1 in 6 on the day symptoms first occurred
- In spite of these variations by gender, males and females were broadly similar in the types of treatment received (angioplasty, stenting, CABG etc), implying that women were more likely to be undertaking planned procedures, whilst men were more likely to be being treated as an emergency
- For more than 3 out of 4 men, the main influence on encouraging healthy lifestyle choices was advice from spouses and other family members; conversely, 75% of women were more likely to be influenced by booklets, media campaigns etc
- People in urban areas were twice as likely to be influenced by NHS staff in adopting lifestyle changes than people in rural areas
- Of those people who suffered a heart attack, people in rural areas were twice as likely to dial 999, compared to people in urban areas
- In terms of social deprivation, people in less deprived areas were more than twice as likely to recognise symptoms, particularly of a heart attack, and to seek help more quickly – 3 out of 4 dialled 999 within 30 minutes, compared to less than half in more deprived areas
- People in less deprived areas appeared across the board to identify a wider range of influences on healthy living.
**What could prevent someone seeking immediate help for a heart attack?**

A selection of views expressed by members of CHSS cardiac support groups:

‘Indefinite symptoms, lack of knowledge of symptoms. Reluctance to admit that something is wrong’ (Nairn Cardioactives)

‘By not recognising the symptoms of a heart attack (in my own case I thought it was 'wind' or a stomach upset and if I could be sick it would help). I didn't know I was having a heart attack’ (Back into Circulation, West Lothian)

‘The ill conceived view that they must call their GP or NHS24 first (the delay in getting paramedics there quickly can be fatal) and yet some people still do it’ (Annan Hale & Hearty)

‘Feeling that it couldn’t happen to me and that symptoms were unclear’ (Stirling Healthy Hearts)

‘Not realising what the problem was. Until it happens you have no idea how it feels’ (Inverness Bravehearts)

‘Not recognising it. In my case I thought it was indigestion. GP recognised it 3 weeks later in a blood test’ (Kircudbright Hale & Hearty)

**Motivators for seeking help with heart problems**

‘The majority of patients seen by the service have not actively sought help with cardiac issues in the first instance. In many cases, patients have been aware for a number of months of feeling unwell, but it is not usually until an emergency admission that they specifically seek any help. Anecdotally, patients in low-income or typically deprived areas have spent many years with poor management of risk factors such as smoking, obesity or excessive alcohol consumption. They do not seek to manage these at all until their condition becomes chronic or forces an acute admission.

Some patients express the view that smoking or alcohol are the only enjoyable aspects of their life, rather than undertaking light exercise or healthy eating, particularly in deprived areas.’

CHSS / Fife CARB Benefits Adviser (based on 100 clients referred with cardiac problems)