

MANIFESTO – PUTTING SPECIALISED CARE AT THE HEART OF HEALTH

1. The standard and availability of specialised services is fundamental to a properly functioning NHS

Specialised services should be considered as part of a continuum of care rather than a marginal area.

Specialised services are those which cater for people who have conditions which are rarer or complex and expensive to treat. Cumulatively, these conditions affect a large population and account for 10 per cent of overall commissioning budgets. For example, it is estimated that there are 350,000 with neuro-degenerative diseases, 200,000 people with chronic liver disease, 50,000 with HIV and 37,500 with end stage renal failure. In addition, conditions such as diabetes and rheumatoid arthritis can trigger the need for specialised treatment.

The SHCA would like to see the treatment of those with specialised services properly addressed in the development of national policy and local delivery plans and targets.

2. Effective commissioning is essential

PCTs should be able to demonstrate that they have collaborated in considering all 35 areas of the National Definition Set.

As for other conditions, responsibility for specialised services commissioning currently rests with PCTs. However, given the large planning populations for specialised services the DH has advised PCTs to collaborate to ensure that services and treatments covered by a National Definition Set are commissioned and planned effectively. This is particularly important given the move to local target setting and was underlined in paragraph 15 of the recent DH Planning Framework for 2005-08.

Research commissioned by the SHCA suggests that many Trusts still do not have appropriate collaborative arrangements in place. The SHCA believes SHAs must build on the Planning Framework and ensure that all PCTs have actively considered how best to secure and improve the services in the National Definitions Set.

3. Access to treatments should not be subject to geographic variation

All people with specialised conditions should be given equal access to uniformly high levels of quality care and service and the latest treatments.

For those patients with specialised conditions choice is not as simple as a choice of providers but means the ability make an informed choice about what treatment best suits their needs and the ability to access that treatment wherever they live.

Given the cost of treatment and the lack of national guidelines, the SHCA is concerned that the quality and range of treatments will be eroded as PCTs face financial pressures. A DH tracking exercise found that some cancer networks received less than 60 per cent of the money they expected from PCTs under the first year of the NHS Cancer Plan. Similarly, the Cystic Fibrosis Trust recently discovered prescribing rates for an effective drug varying from 65 per cent in one area to 23 per cent in another.

The SHCA considers that funds for specialised commissioning should be prioritised alongside general services. This will be particularly important given the changes in financial structures which are being introduced such as Payment by Results and practice-based commissioning.

4. Healthcare organisations should be accountable

The delivery of specialised services is an important measure against which the success of NHS reform should be judged

Many people will need to access specialist services in the course of their lifetime and these services are complex to plan and run, involving collaboration between significant numbers of PCTs and across SHA boundaries. Given the move to local target-setting by PCTs there is a danger that the availability and quality of these services will not be adequately monitored.

The Healthcare Commission, with its ability to work across organisational boundaries is ideally placed to ensure that healthcare organisations maintain and advance standards for the vulnerable groups that require these services. The SHCA believes the Healthcare Commission should address this need through a variety of mechanisms including its inspection criteria and thematic reviews.

5. Patients with specialised conditions should be involved in decisions relating to their care

The commissioning process should be open and transparent and involve patients wherever possible

People with specialist medical conditions require high-quality personalised care to meet their needs. In many cases this means giving patients the information and resources to enable them to exercise greater control over how their treatment is planned and delivered.

Currently patient involvement in specialised services is very low and the process by which services are planned and delivered is complex and opaque. The SHCA believes that greater transparency about the commissioning process including a DH map of who is responsible for commissioning services is an essential first step in enabling patients and their carers to take a more active role in the care they receive. Patients with specialised conditions should receive personal care plans in line with the National Target for people with long-term conditions.