



SPECIALISED HEALTHCARE ALLIANCE POSITION PAPER FUNDING FOR HIGH COST TREATMENTS

One of the NHS's most precious strengths is its ability to provide the highest standards of treatment for people unfortunate enough to suffer from rarer and more complex conditions. This strength must not be weakened by the shift towards greater local accountability for the generality of health services. The significance of specialised services in translating medical research into practice, with potentially widening health benefits thereafter, also needs to be recognised.

The Specialised Healthcare Alliance (SHCA) is a broad coalition of 41 patient groups, supported by eight corporate members. It has been set up to campaign on behalf of people with conditions which require specialised medical care. These conditions tend to be rarer and both complex and expensive to treat. Examples are numerous but include certain cancers, cystic fibrosis, haemophilia, HIV and neurological conditions. Accidents or complications of more common conditions such as diabetes can also trigger the need for specialised services. Cumulatively, specialised services are important to a very large number of people.

Given the cash constraints within the NHS and the development of new, sometimes expensive, drugs and other treatments for specialised medical conditions, the Alliance is concerned that the availability of treatments for specialised services is subject to unacceptable variation across the country (post-code prescribing). In many cases, there is an absence of national guidelines or targets for specialised services. However, even when these do exist, for example in the form of NICE guidance, there is considerable variation in implementation between PCTs.

The SHCA recognises that the NHS operates within cash limits and that difficult decisions regarding priorities need to be made. The standard and availability of specialised services is, however, fundamental to a properly functioning, integrated National Health Service and a key criterion by which the success of reforms should be judged. Priorities should therefore be established by commissioners and clinical staff on a rigorous basis with patient-led involvement.

Devolution within the NHS means that local priorities increasingly drive allocation of resources. Whilst this development has many benefits it can unfairly disadvantage patients with specialised conditions who inevitably will be smaller in number and therefore have less of a voice locally. The new commissioning arrangements for specialised services announced in the Commissioning Framework should provide a degree of protection for patients with specialised medical conditions as commissioning will take place across a number of PCTs. However, if they are to be successful it is essential that the new Specialised Commissioning Groups are allocated sufficient resources from PCTs to commission effectively.

In addition to the ethical case for according patients with specialised medical conditions equal access to drugs and services, ensuring patients receive access to treatment for rarer conditions can have wider benefits. The SHCA is concerned that in the current financial climate, with a tendency to silo budgeting, decisions about whether to fund treatment are often made without considering the additional costs elsewhere, such as the cost of palliative care, social service costs and costs in terms of lost employment productivity that arise from refusing to fund treatment.

Moreover, funding specialised treatments is essential if the NHS is to meet the challenges of the future. Specialised treatments are, by their nature, higher in cost and often have lower amounts of clinical trial data to prove their case. This should not be used as a reason for NICE or commissioners to refuse funding for them. Government should work with the manufacturers to enable data collection on cost effectiveness and efficacy whilst funding is made available by the NHS. Specialised research and treatments often eventually benefit those with more mainstream conditions. Many patients with specialised conditions recognise this and willingly participate in clinical trials or contribute to national registers. The role of specialised services in realising the early benefits of innovation is particularly apposite in the light of Sir David Cooksey's recent report on medical research.

Whilst the Alliance recognises the challenges raised by affording those with specialised medical conditions equal access to treatment as those with more common conditions, it believes the Government should ensure that robust funding systems are in place to ensure stable provision for these vulnerable patients.

Accordingly the SHCA urges the widest possible support for:

1. The standard and availability of specialised services being fundamental to a properly functioning National Health Service;
2. The new commissioning arrangements for specialised services being implemented at the earliest opportunity with sufficient pooled budgets attached;
3. For services and treatments not covered by Payment by Results, pooled budgets are imperative;
4. The Department should encourage more consistency of provision of specialised treatments across the country by developing the National Definition Set and including standards of care where appropriate;
5. Where treatment is not approved, the decision-making process should be more transparent and there should be a clear appeals process for patients with support provided;
6. The Government's strategy for medical research needs to recognise the role of specialised services in providing a pathway for innovation.