

## **SUBMISSION BY THE SPECIALISED HEALTHCARE ALLIANCE (SHCA) TO REVIEW OF THE CONSEQUENCES OF ADDITIONAL PRIVATE DRUGS FOR NHS CARE**

The SHCA is a coalition of 42 patient organisations supported by nine corporate members which campaigns on behalf of people requiring 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.

The NHS was born out of the ideal that good healthcare should be available to all, regardless of means. On 5th July 1948, Aneurin Bevan set out the three core principles of the NHS:

- that it meet the needs of everyone;
- that it be free at the point of delivery;
- that it be based on clinical need, not ability to pay.

These three principles have guided the development of the NHS for the past 60 years. The Alliance strongly endorses their primacy and welcomes the support they receive within the terms of reference for the review.

The current review stems from anecdotal evidence of more patients resorting to private payment to secure drugs for which their PCTs refuse funding. This may reflect variations between PCTs or the absence of a NICE appraisal or both but it results in inconsistency and inequity, which the SHCA considers unacceptable in the modern NHS. It highlights the lack of clarity surrounding the NHS rule that individuals purchasing drugs outside the NHS are ineligible for free NHS care, which generates inconsistencies of its own. The Alliance would also emphasise that while this dilemma has arisen most conspicuously in relation to drugs, it is by no means restricted to them and would urge that any adjustments in policy should apply equally to other forms of treatment.

Drawing on the draft NHS Constitution, the SHCA recommends that the emphasis must always be on the NHS providing services and treatments based on national best practice within a process of continuous improvement. The Next Stage Review should help deliver this objective through speedier NICE appraisals and the development of NICE Evidence as a single portal for information on best practice. There is, however, a significant proportion of treatments which will fall foul of NICE's threshold for clinical and cost effectiveness or which will not be appraised given the very small patient numbers involved ie ultra-orphan products.

As things stand, this body of treatments is growing as the NICE threshold fails to keep pace with inflation. The Health Select Committee's recent report on NICE observed that the threshold has remained unchanged while NHS funding has risen nearly threefold. The Alliance recommends a substantial increase in the threshold to ensure that this welcome increase in spending is reflected in all aspects of patient care. In addition, it is important that NICE follows the Secretary of State's directions in their entirety. The Next Stage Review recognises the importance of innovation to the future of the NHS but, in the SHCA's view, NICE pays relatively scant regard to the link between orphan drugs and innovation. Similarly, clinical need should be weighed alongside cost effectiveness in the context of a compassionate NHS; a view supported by the recent NICE Citizen's Council on Quality Adjusted Life Years and the Severity of Disease.

Where, despite such improvements to NICE procedures, it still falls to PCTs to decide on funding of drugs and other treatments, the draft Constitution makes clear that such decisions should be made rationally following proper consideration of the evidence and with a proper explanation where funding is withheld. The Alliance considers that much greater transparency and consistency is essential but has doubts about the capacity of individual PCTs to undertake such work. Specialised Commissioning Groups or, on occasion, the National Commissioning Group might be better placed to do so.

In the Alliance's view, these developments would help to ensure that the NHS provides the best quality of care and treatments, making the need for private payment the exception that proves the rule. Equally, it would be invidious to apply a blanket ban on private payment as a condition of NHS care and might, inadvertently, hold back progress. The Alliance would therefore advocate an adjustment of the rule so that people can pay privately for a treatment denied NHS funding without forfeiting the right to free NHS care, providing their physician considers it clinically desirable. This modification would help to protect patients from meretricious claims, while the risk of a slippery slope towards a two tier service should be avoidable through careful drafting and associated consultation.

Taken as a whole, these changes would produce significant benefits for patients and strengthen the NHS, while enabling it to monitor the effects of privately funded treatments. The extent to which private funding is exceptional should be seen as a measure of the NHS's success.

SHCA  
August 2008