

## **SPECIALISED HEALTHCARE ALLIANCE RESPONSE TO NHS CONSTITUTION CONSULTATION**

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 supports their primacy and welcomes the commitment to them within the draft Constitution.

The NHS constitution stems from the need to safeguard the core principles and values of the NHS and to secure its future by setting clear direction. The constitution brings together in one document NHS-wide values which clearly define the commitments, rights and responsibilities of public, patients and staff. It reaffirms the contract between taxpayer, patient and the state and, along with the Next Stage Review, it aims to transform the NHS into a system that is clinically led, patient centred and locally determined.

The SHCA offers the following comments and proposes specific textual amendments in relation to consultation questions 4 and 5.

### **Section 3 - Purpose and Principles of the NHS**

Q4. Are the statement of purpose and the set of principles right? Are there any principles that should be added?

#### Principle 3

The constitution confirms the commitment of the NHS to innovation and medical research to improve present and future healthcare. This is particularly salient since interventions for rare diseases are increasingly becoming an important source of clinical innovation. It is also important that when patients receive treatment they are able to access information and participate in research from which they might benefit.

However, there is great variation within the NHS on the value of research and the importance of adopting new ideas and innovations. We believe that embedding the concept of an innovative and research-led health service in the

Constitution will go some way to rectifying this and, in the long term, will result in an NHS which is more open to the benefits of emerging ideas and technologies. However, despite a longstanding commitment to innovation, the NHS's record in adopting new technologies and practices remains poor. We would therefore propose the following amendment:

***and through its commitment to the promotion and conduct of research and to the uptake of innovation beneficial to the current and future health and care of the population.***

#### Principle 4

The Alliance welcomes the continued focus on the quality of care and the principle that the NHS must reflect the needs and preferences of patients, their families and their carers. Following on from commitments set out in the 2008 Carers Strategy, carers will be treated as expert partners in care. However, it is important support mechanisms are put in place to help carers develop their skills and confidence.

#### Section 4 - Patients and the public

Q5. Is the list of public and patients' rights clearly explained and accessible to all sections of the population?

#### Access to specialised services

The constitution continues the direction of travel towards local decision making in the NHS but the provision of services for those with rarer or more complex conditions must not be weakened by this commitment to local health needs. The SHCA understands the desirability of ensuring the NHS is more responsive to local needs and the presumption that decision-making is best located as close as possible to the communities it serves. However, regional and national approaches are vital to specialised services which serve local people with rarer or more complex medical conditions. The Alliance would therefore propose the following amendments to the draft Constitution:

**You have the right** to access local ***and specialised*** NHS services. You will not be refused access on unreasonable grounds.

**You have the right** to expect your local NHS to assess the health requirement of the local community and to put in place the services to meet those needs [delete - as considered necessary] ***working with others where necessary.***

#### Nationally approved treatments, drugs and programmes

The right to receive NICE approved treatment is welcomed by the Alliance, since it is not always obvious to patients what this means in practice.

The commitment to work with NICE to ensure approved drugs become available nationally sooner will go some way to address the problem of variation between PCTs. The time during which PCTs have discretion over funding new drugs will be reduced. 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.

Where it 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. This may require central guidance to ensure consistency and equity across the NHS.

The Alliance considers that much greater transparency and consistency is essential and PCTs must have in place proper documented processes. The Secretary of State's direction to PCTs concerning the process to be adopted when making such decisions should, like NICE, take account of clinical severity and innovation as well as clinical and cost effectiveness. The precise wording of the Constitution should await the results of the Richards Review of co-payments and the National Prescribing Centre's review of PCT procedures in considering requests for exceptional funding.

### **Informed choice**

The formal recognition of patient choice in the NHS Constitution and the placement of patient choice as a major determinant of treatment options are welcomed by the Alliance. However to realise this right, PCTs will have to provide information on the quality of clinical services; there is still a long way to go before accurate, reliable and meaningful data that enables patients, working with their doctors, to make fully informed choices about providers becomes available.

Q7. Do you agree with a new legal right to choice about your NHS care?

The new legal right to choice is welcomed by the Alliance. Real choice, however, includes services and treatments as well as choice of provider and is dependent on the provision of accurate information. The Alliance believes patient choice will encourage the NHS to provide services and treatments based on national best practice within a process of continuous improvement.

### **Section 6 – Accountability**

Q13. Do you support the proposal to publish a separate statement of accountability? How can we make this most helpful?

The SHCA strongly supports a separate statement of accountability. The NHS is a national service funded by general taxation and is responsible for spending over £100 billion of taxpayers' money each year. There must be clear and continuous accountability from local to national level within the NHS, depending on the issues concerned. This should include Parliament's role in shaping the balance between the needs of society and the individual in allocating limited tax revenues. In particular, Parliament is best placed to determine the social values which should inform NHS decisions taken on behalf of patients and the wider public, as embodied from time to time in directions from the Secretary of State.