

## **SPECIALISED HEALTHCARE ALLIANCE RESPONSE TO THE HEALTH WHITE PAPER: EQUITY AND EXCELLENCE: LIBERATING THE NHS**

The Specialised Healthcare Alliance is a coalition of 54 patient-related organisations supported by eight corporate members (see Appendix) which campaigns on behalf of the many people with rare and complex medical conditions, whose interests can be overlooked in the context of a locally-focused NHS. Examples are numerous but include certain cancers, cystic fibrosis, haemophilia, neurological conditions and a wide range of services for children. Accidents or complications of more common conditions can also trigger the need for specialised services such as burns, pain management and spinal injuries.

Since its formation in 2003, the Alliance has taken a close interest in specialised commissioning. As a result, it helped bring about the Carter Review (May 2006) of specialised commissioning and supported its major recommendations. The Alliance also submitted oral and written evidence to the Health Select Committee's inquiry on commissioning prior to the General Election. The Committee's report acknowledged that the Carter reforms had led to significant improvements in specialised commissioning but that insufficient progress had been made in their implementation.

This response to the government's white paper *Equity and Excellence: Liberating the NHS* summarises the Alliance's position on key issues affecting the commissioning of specialised services, concentrating on those which will require primary legislation. We will be submitting responses to the individual consultation documents which accompany the white paper. It would, however, be remiss not to welcome in this document the Government's commitment to putting patients and the public first and the proposed extension of choice to choice of treatment.

### **Healthcare outcomes**

The SHCA entirely accepts the desirability of enshrining healthcare outcomes as the central purpose of the NHS. This is, however, dependent on the availability of data, which often remains in short supply. Outcomes also tend to become apparent in the medium to longer term, while issues affecting those outcomes such as timely diagnosis and optimal treatment will be current. For example good quality care for people with conditions such as cystic fibrosis and muscular dystrophy may more than double otherwise very poor life expectancy.

The Alliance therefore recommends that while the NHS should rightly focus on outcomes as the mark of its ultimate success, this should be combined with use of relevant short-term markers to promote improved performance and guard against slippage. These markers might draw on NICE quality standards or their equivalent for rarer conditions.

The proposed NHS Outcomes Framework marks a welcome development which should sustain a more systematic approach to the collection of data, including patient-reported experience and outcomes. This will, however, take some time to deliver and must accommodate rare and complex conditions.

## **National Institute for Health and Clinical Excellence**

The SHCA has great admiration for NICE but is concerned that the rapid growth in the Institute's remit should prove sustainable. In particular, the workload arising from the development of new appraisals, guidelines and standards is generating a growing need to update earlier work. NICE will therefore need to be properly resourced if it is to fulfil a further extension of its remit effectively.

The Alliance is also concerned that NICE's 150 standards for the main pathways of care should not prove detrimental to people with rare and complex conditions. We would recommend that the NHS Commissioning Board adopt a parallel role for such conditions, with a clear understanding as to what should fall to NICE and what should fall to the Board.

## **NHS Commissioning Board**

The SHCA welcomes the establishment of a dedicated NHS Commissioning Board, which should help to re-balance the relationship between purchasing and provision, so vital to the delivery of high-quality care and best value. We are also delighted that the Board will be given responsibility for national and regional specialised services, as defined by the National Definitions Set, which should address the shortcomings in specialised commissioning identified by the Health Select Committee in its report published in March 2010.

At the same time, there are a number of points where we would appreciate early clarification, as follows:

- The number of regional offices and their role will be important in maintaining effective links between the National Commissioning Board and the wider NHS, especially if GP commissioning consortia are local in character. From a specialised commissioning perspective, we would see it as desirable to have not less than eight regional offices to reflect patient flows and the character and culture of different health economies. These offices should facilitate liaison to ensure the engagement and input of GP consortia and effective provision of those primary and community care services best commissioned at local level for people with specialised conditions;
- While it makes sense for the National Commissioning Board to assume responsibility for assessing commissioning from the CQC where GP consortia are concerned, a third party needs to assess the Board's performance for those services which it commissions. The DH would seem best suited to fulfil this role or, alternatively, it could remain with the CQC for those services commissioned by the Board;
- As PCTs focus on supporting the establishment of GP consortia, the danger is that their already inadequate commitment to specialised commissioning will wane with potentially damaging results for patients. We would therefore advocate an early transfer of oversight to the National Commissioning Board, initially working through the existing regional Specialised Commissioning Groups and their constituent PCTs;
- During this period a high priority should also be attached to costing the services covered by the National Definitions Set to enable accurate budgets to be set in 2012/13. A survey conducted by the SHCA in late 2009 found that the extent to which SCGs were commissioning the National Definition Set was highly variable and in no case complete. The SCGs' current levels of

expenditure do not therefore represent the aggregate funds the National Commissioning Board will require for specialised commissioning purposes.

### **GP consortia**

Late diagnosis is a major problem with rare conditions and has important ramifications for clinical outcomes. In a recent study, the King's Fund observed that GP commissioners are likely to turn to referral management when they take responsibility for the bulk of the NHS commissioning budget. It will be important for the NHS Commissioning Board to ensure that this adopts an even-handed approach between over-referral, under-referral and misdirected referral to protect and promote the interests of people needing speedy specialist care.

### **Role of the Secretary of State**

The Alliance understands the rationale for limiting the Secretary of State's role in relation to the running of the NHS. At the same time, in a taxpayer-funded system, it is important that the public has confidence in the accountability of Ministers to Parliament. This balance will need to be carefully struck in the Health Bill if public confidence is to be maintained.

More practically, specialised services by definition cater for larger populations crossing local and regional boundaries, sometimes up to national level. The configuration of services is important in ensuring sufficient patient volumes to support clinical standards and safety on the one hand, while offering the best possible access on the other.

Current overview and scrutiny arrangements mean that proposals to re-configure national services need to be referred to local committees right across England, generating considerable cost and delay. The Alliance sees merit in the NHS Commissioning Board being able to consult on such proposals with the Secretary of State acting as final arbiter.

### **HealthWatch**

The proposed remit of HealthWatch is couched in almost entirely local terms. Specialist providers will usually be delivering services to patients from outside the local area and sometimes right across the country. It is important that HealthWatch makes provision to capture the views of such users to help inform specialised commissioning as well. HealthWatch England may be the most appropriate vehicle for doing so.

### **Foundation Trusts**

In the same way, the governance of Foundation Trusts is largely predicated on local populations even though hospitals providing specialised care may draw the majority of their patients from further afield. Clear provision should be made to protect the interests of this constituency in a reformed Foundation Trust model.

### **Monitor**

The White Paper gives Monitor the role of promoting competition and guarding against purchasers acting anti-competitively. A key tenet of the Carter report on specialised commissioning is that specialised commissioners should be able to designate providers of specific specialised services using a robust, transparent process.

The Alliance supports the Carter report's view that designation of specialised providers helps to secure an appropriate concentration of clinical expertise and activity to safeguard patient access to high-quality, cost-effective services located to maximise geographical convenience. It is important that Monitor's terms of reference recognise the need for some curtailment of free competition in this area.

**Other issues**

While the Alliance welcomes additional resource being made available for the treatment of cancer, there are other people and conditions equally meriting support. We would commend the ethical decision-making framework recently adopted by the Advisory Group on National Specialised Services as a starting point for a more consistent, value-based approach to funding decisions in the wider NHS.

In relation to cutting the costs of bureaucracy, we would caution against an indiscriminate approach recognising, in particular, that specialised commissioning often has amongst the lowest overheads in the NHS.

SHCA  
17.9.10

### SHCA Members

Arthritis and Musculoskeletal Alliance (ARMA)  
Arthritis Care  
ASBAH (Association for Spina Bifida and Hydrocephalus)  
BAPEN (British Association for Parenteral & Enteral Nutrition)  
Behcet's Syndrome Society  
BLISS (premature baby charity)  
Bowel Cancer UK  
British Liver Trust  
British Paediatric Rheumatology Group  
British Polio Fellowship  
British Society for Rheumatology  
Child's Liver Disease Foundation  
Children Living with Inherited Metabolic Disorders (CLIMB)  
Children's Heart Federation  
(The) Children's Trust  
CLIC Sargent  
Contact a Family  
Cystic Fibrosis Trust  
Ehlers Danlos Support Group  
For Dementia  
GBSSG (Guillain-Barre Syndrome)  
Grown Up Congenital Heart Patients' Association (GUCH)  
Haemophilia Society  
Hepatitis B Foundation UK  
International Brain Tumour Alliance  
Kidney Alliance  
Limbless Association  
Lymphoma Association  
Macmillan Cancer Support  
Motor Neurone Disease Association  
MS Society  
MS Trust  
Muscular Dystrophy Campaign  
Myeloma UK  
National AIDS Trust  
National Brain Injury Centre, St Andrew's Healthcare  
National Kidney Federation  
National Voices  
Neurofibromatosis Association  
National Rheumatoid Arthritis Society  
Niemann Pick Association  
Parkinson's UK  
PINNT (Patient on Intravenous and Naso Gastric Nutrition Therapy)  
Primary Immunodeficiency Association  
Progressive Supranuclear Palsy Association  
Pulmonary Hypertension Association  
Rarer Cancers Forum

Scleroderma Society  
Sickle Cell Society  
Sign (mental health and deafness)  
Speakability  
Spinal Injuries Association  
Teenage Cancer Trust  
Terrence Higgins Trust

#### Corporate

Abbott Laboratories  
Actelion  
Baxter  
Bayer  
Genzyme  
Novartis  
Novo Nordisk  
Pfizer