



Spinal Injuries Association (SIA)

Response to: Equity and excellence: Liberating the NHS – a consultation by the Department of Health

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Sent on behalf of: Spinal Injuries Association (SIA)

The Spinal Injuries Association (SIA) warmly welcomes the opportunity to respond to the Department of Health's consultation 'Equity and excellence: Liberating the NHS.'

About SIA

SIA represents the 40,000 Spinal Cord Injured (SCI) people throughout the UK. SCI manifests itself as paraplegia (full or partial paralysis of the lower limbs) or tetraplegia (full or partial paralysis of all four limbs). SCI is a rare and complex impairment to manage. Damage to the spinal cord usually causes a permanent generalised physiological impairment and multi-system malfunction. All the systems of the body function differently to those of a non-paralysed person. Neither such abnormal physiology nor its management figure in the curriculum of medical schools in the UK or abroad. The clinical symptoms and signs of medical and surgical conditions that are taught in medical schools do not apply to patients with SCI because of the loss of feeling associated with paralysis.

With the low incidence of traumatic and non-traumatic SCI (less than 1,000 per year), non-specialist hospitals rarely see a SCI patient. Similarly, a GP might only average a single SCI patient throughout their career.

As part of the Specialised Healthcare Alliance, SIA has supported the major recommendations of the Carter Review into specialised commissioning, 2006. 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 SIA's position on key issues affecting the commissioning of specialised services, concentrating on those which will require primary legislation.

Healthcare outcomes

SIA 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 SCI people will enable a more rapid and thorough rehabilitation, leading to an independent, productive life which might not be echoed by those who are unable to attend a specialist SCI Centre following their injury.

SIA 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 such as SCI.

National Institute for Health and Clinical Excellence

SIA 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 fulfil a further extension of its remit effectively.

SIA 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 such as SCI. SIA 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

SIA 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. SIA is 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 SIA 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, SIA 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, including liaison arrangements to ensure the engagement and input of GP consortia;
- 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. SIA 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 Specialised Health Care Alliance 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.

Role of the Secretary of State

SIA 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. SIA 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.

SIA 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

Whilst SIA welcomes additional resource being made available for the treatment of cancer, there are other people and conditions equally meriting support. SIA 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, SIA would caution against an indiscriminate approach recognising, in particular, that specialised commissioning often has amongst the lowest overheads in the NHS.

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