

## HEALTH SELECT COMMITTEE INQUIRY INTO COMMISSIONING

### SUBMISSION BY THE SPECIALISED HEALTHCARE ALLIANCE

1. The Specialised Healthcare Alliance (SHCA) is a coalition of 44 patient organisations supported by ten corporate members, which campaigns on behalf of people with rare and complex medical conditions for whom key services cannot be sensibly planned, procured and delivered at a local level. It is chaired by Baroness Pitkeathley.

#### **Executive Summary**

2. The principles of world class specialised commissioning pre-date the World Class Commissioning programme and are laid down in the Carter Report of 2006.
3. The genesis of the Carter review was the recognition that Primary Care Trusts (PCTs) were not collaborating effectively in the specialised arena to the potential detriment of people in need of specialised care.
4. The need for collaboration hinges on optimising the development and use of clinical resources for relatively smaller patient populations for whom the NHS is also uniquely well placed to share financial risk.
5. Carter therefore proposed, and the Government accepted, that responsibility for such services should be clarified and rest with the National Commissioning Group for the rarest of the rare and ten regional Specialised Commissioning Group for all other services in a revised National Definition Set.
6. To ensure proper provision and equity of access, Carter laid down that services should be funded through budgets pooled between the constituent PCTs in each SCG on the basis of weighted capitation. Furthermore, to ensure standards of safety and quality, providers should be designated according to agreed service specifications and a full understanding of costs along the patient pathway.
7. Significant progress has been made since Carter, with ten SCGs now in existence and revision of the National Definition Set at an advanced stage. The extent of genuinely collaborative commissioning is, however, highly variable and, in many parts of the country, limited. In particular, despite encouragement in the two DH Operating Frameworks following publication, financial risk-sharing is rare while designation of providers and, more importantly, the knowledge required to underpin it, has scarcely got underway.
8. The reasons for this limited progress more than three years after Carter's adoption by the Government are manifold, including the scale of tasks such as designation and the availability of limited resources. Crucially, however, Carter depends on the willingness of PCTs to share sovereignty and resources in a way which is counter to their instincts and the rhetoric of localism. This

reluctance to implement world class specialised commissioning may well grow as PCTs look to protect local services in the downturn, to the detriment of clinically and cost effective specialised care.

9. The unacceptable consequences of these shortcomings for patients have been highlighted in a number of recent All Party Group reports covering muscular dystrophy, Parkinson's disease and spinal injury.
10. Although the principles of Carter remain sound, the SHCA is doubtful whether PCTs will ever give them sufficient support across the country. At the same time, top-slicing, as employed to fund the work of the National Commissioning Group, is a source of constant and unnecessary resentment. Far better, in the Alliance's view, to build on the foundations which have now been laid by changing funding flows so that money is routed directly to the NCG and SCGs, with the latter sitting in their respective SHAs rather than a lead PCT.
11. Localism is an important principle but the very existence of the NHS confirms its limitations. Local people need specialised services but they cannot be effectively funded and provided at a local level. Dogma about maximising the proportion of funds flowing to PCTs is misplaced. The appropriate commissioning tier should receive its funds direct and be held to account for their use.

#### **Pre-Carter**

12. Prior to the Carter Review and Report, nationally commissioned services were managed and funded within the Department of Health through the National Specialised Commissioning Advisory Group (NSCAG), mainly comprising a range of eminent clinicians and reporting to Ministers. All other specialised services, legally defined as involving planning populations in excess of one million, sat in the NHS but with collaborative commissioning taking place on a purely voluntary basis. In particular, associated guidance from the DH recommended that services with planning populations of 1-2 million should be managed by 25 Local Specialised Commissioning Groups broadly aligned with the then 28 SHAs, while services with planning populations of 3-6 million should be managed by eight Regional Specialised Commissioning Groups. This left huge scope for confusion, not least for planning populations of more than 6 million but falling short of nationally commissioned status.
13. Research published by the SHCA in the spring of 2004 suggested that collaboration between PCTs was for the most part patchy and that large swathes of the Specialised Services National Definition Set had not been addressed. Associated weaknesses included a lack of risk sharing, poor availability of patient data, very limited patient involvement and a general absence of transparency. In the context of increased localism, the Alliance was concerned that money intended for specialised services would be diverted to more pressing priorities at PCT level, with hard evidence being adduced by members such as BLISS and the Terrence Higgins Trust. More

broadly, a typical comment from the NHS was that specialised commissioning always tended to be an afterthought in health policy.

### **Carter**

14. Against that background, the SHCA warmly welcomed the decision of Lord Warner, then Minister of State for Health, to invite Sir David Carter to undertake an independent review of specialised commissioning and was pleased to sit on the review group.
  
15. The Carter review superseded an Audit Commission study of specialised commissioning. The Audit Commission nevertheless fed in the results of a survey it had conducted which found that there was considerable geographic variation in approach to specialised commissioning, a need for greater engagement in the commissioning process and a lack of management tools for commissioners. Furthermore:
  - the influence of patients and SHAs on commissioning was seen to be unimportant;
  - understaffing and skills problems appeared widespread; and
  - about half of growth funds were reported as being diverted in-year by individual PCTs to other services.
  
16. The Carter Report concluded that much more robust and consistent ways of working were required with key recommendations including:
  - a) a National Specialised Services Commissioning Group (NSSCG) to coordinate specialised services commissioning across all regional groups (see below) and to provide a framework within which binding commissioning decisions requiring pan-regional agreement can be made;
  - b) national commissioning to be conducted where appropriate by a sub-group of the NSSCG, the National Commissioning Group using transparent and published criteria in providing advice to Ministers on designation;
  - c) responsibility for determining the arrangements for all other specialised commissioning to be vested in ten Specialised Commissioning Groups aligned with the new Strategic Health Authority boundaries and acting on behalf of all PCTs in the SHA area;
  - d) budgets for SCGs pooled from PCT allocations to promote robust, long-term commissioning arrangements and manage financial risk;
  - e) periodic designation of specific service providers to ensure quality and safety with strong patient and public input;
  - f) SCGs to work closely with their clinical networks to ensure that commissioning and investment plans support the delivery of integrated care;
  - g) the DH to initiate an immediate review of the Specialised Services National Definitions Set with a view to more balanced and consistent coverage with clear criteria for inclusion;
  - h) SCGs and the NCG to contribute annually to an NSSCG website giving details of their commissioning arrangements including contact details for the lead commissioner for each specialised service;

- i) SHAs to ensure strong performance management of specialised services commissioning, ensuring that PCTs have appropriate arrangements in place for collaborative commissioning and that SCGs are working effectively.
  - j) performance assessment of PCT commissioning by the Healthcare Commission to include the commissioning of specialised services;
  - k) a higher profile for specialised services and their commissioning arrangements within and outside the NHS with commissioning given greater prominence in career options for managers and clinicians.
17. The SHCA warmly welcomed the report, which was rapidly adopted in all its essentials by the Government. The focus of attention then moved onto implementation.

### **Post Carter**

18. The starting point for implementation of Carter was establishment of the SCGs, recognising that the culture of collaborative commissioning was relatively well developed in some regions eg West Midlands and in others hardly at all eg South West. In particular, the report recognised the importance of binding decision-making and delegated authority with a view to SCGs and the National Specialised Commissioning Group being able to take decisions without constant referral back to constituent PCTs.
19. The report also set out a number of timelines for key elements of specialised commissioning. These included immediate revision of the National Definition Set; initial pooled budgets for a specified minimum list of 25 services by April 2007, expanding to all services in the NDS by April 2008; full quantification and costing of disaggregated service costs by April 2008; and designation of all specialist providers by 2010.
20. The timetable for implementation was probably always over-optimistic but nevertheless the rate of progress has been disappointing. After a slow start, revision of the National Definition Set is now advanced with completion projected for next year. Carter had, however, envisaged the NDS encompassing nationally agreed service standards and clinical outcome measures, whereas in practice it has been largely limited to a clinical codings exercise. Delivery of service standards and the like shifted to the designation programme; a legitimate decision undermined by the glacial rate of progress.
21. More fundamentally, while many SCGs have apparently large budgets, in some cases approaching £1 billion, very few of these are genuinely pooled in the sense that risk is shared across the region regardless of the incidence of a disease in a particular PCT.
22. The three main approaches to budget calculation are actual by PCT, three-year weighted average, again by PCT but helping to even out some of the peaks and troughs, and weighted capitation, where the cost of a service is shared according to the number of people in a PCT.

23. The incidence of rare and complex conditions requiring specialised services is arbitrary but can generate very substantial costs in a particular PCT. At the very least, this means that major treatment decisions are likely to be referred back to individual PCTs, undermining the role of the SCG in a way which is completely at odds with the principles of Carter. More importantly, it can put pressure on optimum care, for example if a large potential bill arises towards the year-end there may be a temptation to delay treatment.
24. As one commissioner put it, in theory there would be financial sense in re-housing families with some rare conditions in neighbouring PCTs. It is perverse that this situation should arise when the taxpayer funded nature of the NHS initially shares risk across the entire population.

### **SCG Survey**

25. As part of its preparations for the Committee's inquiry, the Alliance undertook a small survey of SCGs. A full set of ten replies has been received but it has not been possible to analyse these fully before the deadline for submissions. The following observations may, however, be of interest to the Committee:
- None of the SCGs commissions all of the services in the National Definition Set. The maximum number of service categories reported to be fully commissioned by any SCG is 28 out of 36 and the minimum is six. There is scope for confusion between individual services and NDS categories which may cover several services eg in the field of cancer, neurosciences or mental health. It is common for services to be planned but not procured or planned or procured by some PCTs within the SCG only;
  - Mapping and costing of services is often dependent on their coverage by Payment by Results, which is limited, and otherwise based on historical costs;
  - The nature of PCT and SHA representation at SCG meetings is highly variable with PCT Chief Executives attending in significant numbers in some regions but scarcely at all in others. Similarly SHA representation ranges from Director-level to not at all;
  - The very welcome achievements cited in the responses tend to concentrate on issues such as IVF, neonatal intensive care, renal services and mental health.
26. We separately ask SCGs to let us know each year who is the designated lead commissioner for each service category within the National Definition Set. Carter recommended that such information should be included on SCG websites as an aid to greater accountability and transparency but few do so. It is notable that there seems to be considerable turnover in the individuals specified; that they often cover large swathes of services; or that no one is nominated, even on occasion for services which the SCG reports as being collaboratively commissioned.

### **Patient Perspective**

27. SCGs deserve congratulation for bringing about significant improvements in some services. This is perhaps best described in an article by Nicholas Hunt

(Health Service Journal 8<sup>th</sup> January 2009), Director of Service Development at Royal Brompton and Harefield Trust, which highlights the transformation in knowledge and expertise since responsibility for commissioning cystic fibrosis services transferred from PCTs to SCGs. This is seen as having brought about savings to the health economy as well as better standards of care, crucially combining delivery in tertiary and local settings. The Cystic Fibrosis Trust is thought to share much of this view.

28. Less positively, a recent All Party Parliamentary Group on Muscular Dystrophy concerning Access to Specialist Neuromuscular Care observes a dearth of engagement by specialised commissioners with poor diagnosis, a large gap in mean life expectancy for those with Duchenne from 19 years in the South West to 30 years in the North East and closure of specialised wheelchair services at Stanmore without adequate replacement, despite their specialised status.
29. The All Party Group for Parkinson's Disease has also published a report recently into Access to Health and Social Care. In particular, the report notes difficulties in obtaining funding from PCTs for deep brain stimulation. This was originally commissioned at national level and is one of the few services which all SCGs claim to commission, underlining questions about the robustness of funding arrangements, which should preclude the need for exceptional funding decisions by PCTs.

### **Assessment**

30. In general, the principles of specialised commissioning laid down in the Carter Report hold good. Significant progress has been made in a number of areas but the rate of progress is slow and the wider NHS's commitment in some doubt.
31. When Carter was published, the hope was that the clamour for services to be commissioned nationally, with discrete budgets top-sliced from PCTs, would die down and that there would be more two-way traffic, with services moving in and out of nationally commissioned status. Thus far, these hopes have been disappointed with the number of nationally commissioned services rising from 33 in 2005/06 to over 50 today. The problems reported with deep brain stimulation since it was devolved to SCGs provide some explanation.
32. The structural problems at the heart of SCG commissioning are perhaps best exemplified by the attitude of regulators and its status within the DH's current World Class Commissioning programme. As a consequence of the purchaser provider split, the Healthcare Commission extended its sphere of interest to commissioning. The Alliance, however, had extreme difficulty in persuading the Commission to take an interest in specialised commissioning because legal responsibility lay with PCTs, even though they vested that responsibility in SCGs in relation to specialised services. The first indications are that the Care Quality Commission will similarly struggle to square the circle, leaving specialised commissioning in a form of regulatory limbo.

33. This phenomenon is also exemplified by the World Class Commissioning programme. The SHCA pressed vigorously for WCC to apply to specialised services with a separate assurance scheme recognising the different arrangements involved. The DH eventually produced documentation for World Class Specialised Commissioning but this only partially reflected those differences and, crucially, was excluded from the mandatory assessment applied to PCTs. In consequence, SCGs are free to adopt WCSC as they see fit or not at all, again leaving 10 per cent of NHS activity in limbo.
34. Structural and financial issues come together in the reluctance of PCTs to share risk on the basis of weighted capitation. Although risk sharing has been separately encouraged by the Audit Commission, the propensity to do so is probably in inverse proportion to the need. The effectiveness of the approach is therefore dependent on having a sufficiently large pool of risks to ensure that what an individual PCT loses on the swings it will gain on the roundabouts. The incremental approach to implementation of the National Definition Set means that PCTs are likely to look at individual risks and prefer to hold on to what they consider to be their money.
35. In these two interrelated respects, the Carter arrangements have shown themselves to be vitally flawed, putting SCGs in an invidious position, which is likely to worsen as financial pressures grow in the NHS.

### **Conclusion**

36. The NHS now has the right tiers of commissioning to deliver high quality services to patients depending on the nature of their condition at practice, local, regional or national levels. In the case of specialised services, however, there are flaws which need to be addressed:

#### National Commissioning Group

37. NCG services are ultimately determined by Ministers but funded through top-slicing of PCT budgets. Ministerial involvement makes sense given the strategic nature of such decisions but top-slicing causes considerable and avoidable friction. It would be better for money to be channelled directly to the NCG with performance management conducted by the Department.

#### Specialised Commissioning Groups

38. SCGs sit in a financial and regulatory limbo with SHAs given the task of performance management but responsibility formally residing with PCTs, while pooled budgets exist in largely nominal terms from a risk-sharing perspective. SCGs have considerably more potential to deliver clinically and cost effective specialised services than has yet been realised. Consideration should therefore be given to channelling funds direct to SCGs and re-locating them at SHA level.