10 Specialist commissioning

What is specialist commissioning?

Definition of specialised services

The Department of Health defines specialised services as those with low patient numbers but which need a critical mass of patients to make treatment centres cost effective. This requires a population base that is much larger than those of individual PCTs (usually over 1 million). Currently, 36 specialised services are designated within the Specialised Services National Definition Set (2nd edition, 2002), although the usefulness of these definitions in reality has been questioned. IMDs are included under three of these sets:

- specialised services for women’s health
- medical genetics
- specialised services for children.

Particular challenges for these services include training specialist staff, supporting high-quality research programmes, and making the best use of scarce resources like expertise, high-tech equipment and donated organs. Specialised services are subject to different commissioning (planning, procuring and monitoring) arrangements from other NHS services.

Organisation of Specialist Services Commissioning

National arrangements

The NSCAG was established in 1996 to facilitate the commissioning and funding of certain specialised services. Its aims are to ensure that patients with uncommon conditions have access to high-quality care, that financial and clinical risks to PCTs are minimised, and that provider units have sufficient resources to provide and develop their services. NSCAG has a series of very tight criteria for including specific conditions under its remit. At present, only LSDs, including Gaucher and Anderson-Fabry disease, are included from IMDs. NSCAG evaluates provider units applying to provide services, designates provider units for service provision, pays the costs of provider units whilst they are being evaluated, and produces service guidelines. For new services, additional funding is derived from NHS growth money or by a levy on PCTs up to the level of current NHS funding (if the service is or has been already provided by the NHS).

NSCAG has established a subgroup to advise on genetic disorders, the Genetics Commissioning Advisory Group (GenCAG); and the UK Genetic Testing Network (UKGTN), a subgroup of GenCAG, advises on genetic testing.

Other commissioning arrangements in England

Until 2002 specialised services were commissioned by eight Regional Specialist Commissioning Groups (RSCGs). These groups were based on the eight regional offices of the Department of Health. In April 2002 the NHS was reorganised after the report *Shifting the Balance of Power* was published, and PCTs (rather than health authorities) assumed responsibility for commissioning the bulk of NHS services. At the same time, the eight regional offices were absorbed into four Directorates of Health and Social Care, although the eight RSCGs remained. Specialised services were also removed from previous arrangements for cross-boundary funding. These changes prompted a review of specialised services commissioning in 2003. New guidance has been issued based on this review and the results of consultation. PCTs are responsible for establishing collaborative arrangements for commissioning specialised services. These collaborative
Commissioning groups are known as Local Specialised Commissioning Groups (LSCGs) and Specialised Commissioning Groups (SCGs). These groups aim to ensure that:

- Service specifications include all aspects of the patient journey and take into account recommendations from NICE and other national groups or strategic frameworks.
- There are agreed data sets to monitor activity and outcomes (clinical and financial).
- Clinical and financial risk assessments have been carried out.
- Appropriate consortia and risk-sharing mechanisms are in place for very high-cost conditions with unpredictable and highly variable incidence rates.

LSCGs are usually coterminous with Strategic Health Authorities (10–15 PCTs) and have a planning population of around 1 million to 2 million. SCGs usually involve 2–5 LSCGs (45–50 PCTs), with a planning population of 3 million to 6 million. Each group is supported by its own commissioning team. All PCTs belong to LSCGs and all PCTs are represented on SCGs. Strategic Health Authorities are responsible for approving the arrangements and performance management.

Nevertheless, commissioning arrangements for the planning and procurement of services vary within individual SCGs, ranging from direct procurement by PCTs to risk sharing across all member PCTs. Specialist advisory groups may be established to support LSCGs and SCGs. A recent development in medical genetics has been the creation of formal, managed supra-regional networks of molecular genetic laboratories. The commissioning arrangements for these networks involve several SCGs, usually with one taking lead responsibility.

There is also no standardised approach to commissioning within SCGs. Each provider and commissioner therefore needs to understand what the local arrangements are. This complexity means that the implementation of national programmes can be challenging and is of great concern for IMDs.

**Survey of specialist commissioning groups**

A survey of SCGs was undertaken as part of the review process. Commissioners were asked about the following:

1. Local processes for commissioning IMDs.
2. How engaged specialist commissioners were with IMDs:
   - Whether there were any plans to review IMDs.
   - Service specifications and service level agreements (SLAs).
3. What issues were thought to be important when commissioning IMDs.
4. Whether existing arrangements were adequate and, if not, how they could be improved.

Thirty-one commissioners were contacted by email with a supporting letter and an electronic version of the questionnaire. Commissioners were reminded again if responses were not received within one month of the initial contact. A total of 17 replies (55%) was received from commissioners responsible for 184 PCTs. The results are summarised below.

1. **Have IMDs been reviewed / are there any plans to review IMDs?**

Four groups had reviewed IMDs and, of these, one was preparing a business case to establish a regional service for IMDs. None of the remaining groups was planning to review IMDs.

2. **Are there separate service level agreements for adult and paediatric services?**

None of the groups had separate service level agreements for adult or paediatric services.
3. **What mechanisms are there for dealing with cost pressures and service developments?**

There was general agreement that these were dealt with under existing arrangements on a case-by-case basis, unless specific business cases were received from providers or were dealt with through other mechanisms – most notably NSCAG (for LSDs). Three groups commented that other NHS issues were more likely to be prioritised over IMDs.

4. **How can commissioning for IMDs be influenced?**

A number of different responses were obtained. The majority felt that existing arrangements were generally adequate. NSCAG received a number of supportive comments (4/17), and others suggested that a supra-SCG network (other than NSCAG) might be useful (6/17). Two groups identified the need for clear and quantifiable guidance with protocols, quality standards and targets. Two groups felt that a specific national definition for IMDs would be helpful; one group even suggested a national service framework for IMDs and a national register to provide data on national incidence and prevalence. A number of groups highlighted a need for greater education for commissioners about IMDs to help with their work (4/17). One group believed that patient groups could be a powerful influence, although the mechanisms for this were unclear. One also felt that until a patient required specialist (and expensive) drug treatment, PCTs and commissioners were unlikely to consider IMDs as an issue, especially in light of their low incidence rates.

5. **What are the key issues for commissioning IMDs?**

A number of commissioners identified equity of access and evidence of clinical and cost effectiveness as key issues, as for other specialised services in general (4/17). Lack of information about the numbers of patients, where they were being treated and associated costs were also common concerns (5/17). A number highlighted funding issues and especially the cost implications of expensive enzyme replacement therapy (ERT) (6/17). Another group suggested that IMDs should be commissioned within their disease specialty and funded through payment by results. Other issues raised were lack of capacity, lack of knowledge about IMDs, workforce planning and sustainability, management of emergencies, and the transition from paediatric to adult care settings. One group commented that commissioning should be needs led.

6. **What improvements should be made to existing arrangement?**

Only one group felt that the existing mechanisms were ‘not broken’ and did not require fixing. The formation of a national network of commissioning groups for strategic planning and provision was a common theme from the responses received, with an identified lead for specific conditions (5/17). Funding through national capitation was proposed as one mechanism for funding, as long as there was equity of access to services. Risk-sharing mechanisms were also supported, and a number of groups felt that these should be strengthened. Again, the NSCAG model was identified as one potential model for supra-SCG service planning provision.

**What are the key issues for IMD commissioning?**

As described above, there is considerable variation in the way that specialised services are commissioned in England. This means that there are difficulties in developing a coherent national approach for IMDs, and problems for those planning or providing new services. Commissioners, providers, users and their representatives have identified a number of key problems. These include the following:

- Patients with IMDs may be managed by specialist providers or by generalists; this second group of patients need to be incorporated into specialist commissioning processes.
IMD commissioning should move from service-based commissioning to needs-based commissioning.

- Adequate access to appropriate service centres.
- Ensuring that there are adequate adult services to manage the transition from paediatric to adult settings, especially as the outcomes for a number of IMDs are improving and more people are surviving into adulthood.
- Developing clinical networks and multi-disciplinary teams.
- Training and provision of key support staff, especially dieticians and nurses.
- Funding, especially for expensive ERT.
- Lack of information to support the commissioning process: numbers of patients, where they are treated, associated costs, quality and outcomes.
- Appropriate service planning for patients in a decentralised NHS.
- Training and workforce: both for metabolic physicians and allied professionals, especially specialist nurses and dieticians.
- NHS quality: equity of access for patients with rare disorders.

**How to achieve forward progress**

The process of commissioning for IMDs needs to be strengthened, so that patients with these disorders can receive accessible, high-quality care. NSCAG has provided one very successful mechanism for commissioning certain specialised services, most recently for the LSDs. However, it is unlikely that NSCAG will expand its remit to cover other IMDs. NSCAG requires very clear boundaries for services and, given the number and heterogeneity of other IMDs, it is very difficult for them to define appropriate limits. The other issue is that in the current decentralised NHS structure, NSCAG does not wish to further reduce the role of PCTs and the other specialised services commissioning groups.

Therefore, another model for non-NSCAG national commissioning would be useful. A recent collaboration for pulmonary hypertension may provide an alternative. Four lead commissioners to cover the whole of England were identified and a national service has been commissioned using this model. Other options to achieve progress are to focus on services for certain specific IMDs, with the aim of using them as catalysts for developing a range of services that would also be applicable to other IMDs.

**Recommendations**

The Department of Health and other national bodies (such as the Genetics Commissioning Advisory Group, Royal Colleges, professional associations such as the British Inherited Metabolic Disease Group and patient groups) have a key role in the following:

1. Raising the profile of inherited metabolic diseases and the importance of developing comprehensive and equitable specialist services across the UK.
2. Enabling the commissioning processes for inherited metabolic diseases through such mechanisms as:
   - a national supra-Specialised Commissioning Group network or other commissioning mechanism that includes service planning, procurement, provision and monitoring, risk-sharing and funding arrangements
   - enabling commissioning that is based on patient needs rather than current provision
   - consideration of inclusion of inherited metabolic diseases in the National Definitions Set for Specialised Services.
3. Providing support for specialist commissioners by:
   - education about inherited metabolic diseases
• developing information to support the commissioning processes, including minimum
data sets, cost and quality information, number of patients and their use of specialist
and other services.

4. Supporting developing services by:
• establishing a national register for inherited metabolic diseases
• setting up a working party including workforce development members to develop and
  implement educational programmes and training based on required competencies and
  predicted workforce requirements
• supporting the infrastructure for a national laboratory and clinical network.