

FUTURE CONSIDERATION OF HIGHLY SPECIALISED SERVICES, PRODUCTS AND TECHNOLOGIES

The Specialised Healthcare Alliance is concerned that a moratorium on the work of the Advisory Group for National Specialised Services (AGNSS) might presage its abolition without an adequate replacement representing the needs of people with very rare diseases. For the reasons set out below, the future of AGNSS deserves early consideration and debate.

A moratorium has been announced on the consideration of new highly specialised services, products and technologies by the Advisory Group for National Specialised Services (AGNSS), pending the NHS Commissioning Board assuming responsibility for commissioning specialised services in April 2013. The future of AGNSS is uncertain thereafter.

AGNSS was established in 2010 following the Department of Health's consultation on *Strengthening National Commissioning*. A major strength of AGNSS is its multidisciplinary composition, with representation for the Royal Colleges, alongside commissioners, a health economist, an ethicist, patient and lay representatives. This has enabled AGNSS to act as a single source of reliable advice to Ministers on highly specialised services, usually involving patient populations of less than 500.

AGNSS's ethical decision-making framework

In the course of its work, AGNSS developed an ethical decision-making framework to guide its assessments, which takes into account best practice, societal gain, reasonable cost and health gain, to ensure value-based decisions can be made. In practice, this has meant targeted investment facilitating more effective and efficient services for small, dispersed patient populations and in strategic technologies such as ECMO (extracorporeal membrane oxygenation), which proved invaluable during the recent swine flu epidemic, and proton beam therapy.

Ministerial involvement

The moratorium might reflect the view that new commissioning arrangements under the Health and Social Care Act 2012 will make it inappropriate for Ministers to determine which services, products and technologies the NHS Commissioning Board should fund. Clearly, this relationship will need to be set up on an appropriate footing. The generality of specialised services meeting the four factors in the Act will, however, be prescribed in Regulations. Highly specialised services will presumably be similarly prescribed. AGNSS as currently constituted would therefore be compatible with the Act. Ministerial involvement in strategic decisions such as ECMO would also seem desirable.

Devolved administrations' access

As a further consideration, the recommendations made by AGNSS through use of its decision-making framework, due to the small patient numbers involved, are almost by definition relevant to the whole population of the UK, and not just England. To ensure that patients living in the other home countries are properly represented, it might be more appropriate to keep AGNSS or any equivalent working to Departmental level to facilitate cross-border consultation, in keeping with the current consultation on a UK rare disease plan. This would also enable continued Ministerial involvement.

Treatments for very rare conditions

AGNSS is also important as a means of evaluating highly specialised products and technologies inappropriate for consideration by NICE but of great importance to the patients and families concerned. In a debate on 30th April 2012 about a strategy for rare diseases, the Minister of State (Simon Burns MP) appeared to suggest that value-based pricing will supersede the need for separate arrangements for treatments for very rare conditions but that alternative options will be explored in case of need. The Alliance strongly advocates that the interests of patients with very rare conditions should be protected until value-based pricing has been proven to accommodate the different evidence available for the smallest patient populations and that the AGNSS arrangements should meanwhile remain in place.

The Specialised Healthcare Alliance is a coalition of 76 patient-related organisations, supported by 11 corporate members, which campaigns on behalf of people with rare and complex conditions.