

## Briefing for MPs

2nd reading: House of Commons

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Prepared by Genetic Alliance UK

### Commissioning for patients with rare diseases

We are deeply concerned that there is no specific provision in the Bill to identify who has the responsibility for planning or funding treatments for those in need of specialised services that cannot reasonably be commissioned by GP consortia.

Currently, specialised care is commissioned on a regional basis by Specialised Commissioning Groups (SCG) for the outgoing Strategic Health Authorities, and on a national basis by the National Specialised Commissioning Team (NSCT – future uncertain).

Clause 11 inserts new section 3B to the NHS Act: “Power [for the Secretary of State] to require [NHS Commissioning] Board to commission certain health services”. Subsection (1)(d), the explanatory notes to the Bill explain, includes specialised services; but the explanation is vague and does not mention the current organisation with this role, the National Specialised Commissioning Team:

*“It is intended that the services covered by this regulation making power will, for example, include services described as “specialised services” for rare conditions, which are currently commissioned nationally by Strategic Health Authorities rather than regionally by groups of Primary Care Trusts for each Strategic Health Authority region because of their low volume and high cost for example.”*

It is not clear if this refers to national commissioning by NSCT, regional commissioning by SCG, or both.

**Possible question for debate:** Will the Secretary of State for Health explain the NHS structures and systems by which specialised healthcare will be commissioned and provided after the implementation of the NHS reorganisation, and who will specifically be accountable for the delivery of specialised services?

### Advocacy for patients with rare diseases

The local remit of Local Healthwatch organisations will not provide adequate advocacy for those with rare conditions and those who access specialised services commissioned by the NHS Commissioning Board.

**Possible question for debate:** Can the Secretary of State explain how patients who receive specialised care outside of their local area will be helped by Local Healthwatch organisations? Can the Secretary of State guarantee that HealthWatch England will provide this advocacy role for those receiving specialised services?

## Provision of unprofitable, low-volume services

Foundation Trusts will have the freedom to determine the services they wish to provide. We are concerned that measures to ensure continued provision of unprofitable services, services with a low volume of need, and multidisciplinary services which combine inputs from experts employed by different NHS bodies are inadequate and may lead to gaps in service provision for those with uncommon health needs.

Possible question for debate: Can the Secretary of State clarify that Part 3, Chapter 3 “Designated Services” of the Bill gives Monitor the power to compel service providers to deliver vital services for special needs, such as rare genetic conditions, should no NHS Foundation Trust decide to make these available as part of their overall plan; or does this only refer to continuity of service in case of bankruptcy or other catastrophic failure of an existing service provider?

## Inequalities in healthcare provision

There are many types of healthcare inequality in the NHS. One area in which inequalities are apparent is in the delivery of healthcare to those with specialised healthcare needs. The Secretary of State is given a duty in Clause 3 of the Bill to reduce inequalities in the benefits that the people of England obtain from the health service.

Genetic Alliance UK would like assurances that these endeavours will include work to reduce the disparity in health care between those with rare and complex conditions and those with more common disorders.

Possible question for debate: Given that the Bill gives a specific duty to the Secretary of State to reduce inequalities in health care, can he say what mechanisms he envisages putting in place that will address this issue in respect of the differences that may arise based on geographical variations, ethnic differences or variations in the prevalence of conditions that make it more difficult for those with rare and complex conditions to receive care of equal quality to those with more common disorders?

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We will provide further briefings as the Bill progresses. We are happy to discuss any of the issues raised here, or to discuss in greater detail how the Bill will affect those with genetic conditions, and those who require specialised healthcare. Please contact:

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Genetic Alliance UK (formerly Genetic Interest Group) is the national charity supporting all those affected by genetic conditions. Genetic Alliance UK aims to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. Our membership represents more than 130 voluntary organisations working for a wide range of conditions, many of which pose complex health and social care needs.

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