



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

Department of Health

Liberating the NHS

Regulating healthcare providers

Response by Genetic Alliance UK

Introduction

1. 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.
2. A baby with a genetic condition is born every half an hour in the UK; of these only 4 in 10 will have their condition cured or ameliorated, the rest will die or live with a lifelong chronic condition. Most of the patients and families supported by our members are frequent users of the NHS and require good quality coordinated care from a wide variety of local, regional and national centres in many areas of specialisation.
3. We are grateful for the opportunity to comment on this consultation. This response has been endorsed by the trustees and members of Genetic Alliance UK.

Question 21: What action needs to be taken to ensure that no-one is disadvantaged by the proposals, and how do you think they can promote equality of opportunity and outcome for all patients, the public, and where appropriate, staff?

4. We are concerned that the proposed increases in the freedom of Foundation Trusts will create the potential for gaps in service provision unless there is a clear strategy, enforced and policed, for ensuring that the full range of services is available to patients. Experience to date of the tariff system has shown that Foundation Trusts can be reluctant to develop services which are complex, expensive and only address a small patient community without specific incentives such as those provided by NHS Specialised Services. In freeing Foundation Trusts to take greater charge of their own development, care must be taken not to introduce perverse incentives that will promote the avoidance of certain types of service development.

5. Tariff prices will need to reflect the realities of clinical service delivery. For example, clinical genetics works on an outpatient basis but the typical appointment time is three quarters of an hour. Standard outpatient tariff notes make this economically unviable for the Trust hosting the service unless special arrangements are made to avoid this. Professional groups such as the British Society for Human Genetics have generated expertise on tariff issues, this should be used by the NHS Commissioning Board and Monitor when developing frameworks and model contracts.

Alast Kent.

Alastair Kent
Director