



Genetic Alliance UK
Supporting. Campaigning. Uniting.

Consultation Response

NHS Future Forum

Educating and training of health and care professionals

Response by Genetic Alliance UK

1. Genetic Alliance UK 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 140 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.

What aspects of educating and training the health workforce needs improving? In particular, what are the skills and behaviour that need more development?

4. Education and training regarding both genetics and genomics is becoming increasingly important as the pace of change in the two fields becomes increasingly rapid. Genetic testing is becoming cheaper and more accurate. Non-invasive pre-natal diagnosis will hit the mainstream soon. Conditions that were previously considered to be common multifactorial conditions, such as cancer and heart disease, are fragmenting into rarer genetic conditions. It is important that our healthcare professionals, whether specialists or general practitioners, keep pace with these changes.
5. There are many thousands of rare genetic conditions. While we would not expect all medical practitioners to have expert knowledge on individual rare diseases, we believe that all doctors should be aware of the strong likelihood that they will see patients affected by rare disease during their careers and aware of the possible courses of action in such an eventuality.
6. Many of our member charities' members report barriers to treatment of the genetic conditions they support at the primary care level, such as difficulties in achieving referral to specialist care. We believe greater awareness of rare disease across the medical professions would begin to mediate this problem.

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7. The House of Lords Science and Technology Committee published a report¹ on report on genomic medicine in 2009. We would like to draw the Future Forum's attention to this. The Human Genomics Strategy Group is soon to publish a report on engagement and education in genetics and genomic medicine. We believe the Future Forum would find this useful also.

Alastair Kent.

Director
Genetic Alliance UK

1. House of Lords Science and Technology Committee, 2nd Report of Session 2008–09, Genomic Medicine, Volume I: Report
www.publications.parliament.uk/pa/ld200809/ldselect/ldsctech/107/107i.pdf