

**British Humanist Association
47 Theobalds Road
London WC1X 8SP**

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**Human Genetics Commission
Consultation on the supply of genetic tests direct to the public – BHA response**

The British Humanist Association (BHA) is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

Humanists generally support scientists and researchers in their quest for knowledge and the improvement of our health, and understand the potential benefits of genetic testing. The practical and ethical problems raised by the consultation are of interest to us as ethically concerned members of society, but they also strike us as being almost insuperable in a global free market, where advertising may be done on the internet and testing in another country.

For these reasons we confine ourselves to answering just a few of the specific questions in the consultation document, and to offering the opinion that in the privatised free market that seems almost inevitable, education of the public – about the quality and implications of information that can be derived from genetic testing, and about the advantages and disadvantages of knowing one's own genetic characteristics – and counselling will be crucial. We are not convinced that knowing so much more about one's own genetic characteristics will necessarily contribute to the individual's health or happiness, or the sum total of human happiness and welfare. On the other hand, humanists often have a commitment to personal autonomy and informed responsible choice, and over-regulation of genetic testing might well seem unnecessarily paternalistic to some.

Q5: There seems no rational reason to distinguish between genetic testing and other kinds of medical testing – both in the regulation of the industries supplying such tests, and in the way the information derived from such tests is handled, for example, who has access to such information and the necessity for appropriate counselling.

Q11: Yes, such services should be restricted to adults capable of informed consent, applying for information about themselves. Results should be confidential, restricted to the client and his/her GP.

Q13: Such information might best be delivered through GPs, as well as being recorded by them, with appropriate consent.

Q17: It is likely that most types of test will require some form of counselling, even if it only to reassure the client that no further action is required, or to inform him that no further action is possible. This could well, as this section of the consultation document implies, put additional strains on an already overstretched NHS and GPs, and is therefore a matter of concern.

Q18: Education is vital. It would promote realistic expectations and, perhaps, discourage people from seeking genetic information which cannot help them in any way, and thus help to avoid overloading the NHS with unnecessary test results and counselling.

Q25: It is possible that strict controls, as in Option 4, are desirable. Whether they are possible in practice is debatable.

Completed on behalf of the British Humanist Association by Marilyn Mason, education officer, in consultation with Hanne Stinson, executive director.