

Direct to consumer genetic testing in Europe

Pascal Borry, K.U.Leuven, Pascal.Borry@med.kuleuven.be
Heidi Howard, K.U.Leuven, Heidi.Howard@med.kuleuven.be

Background

With ongoing genetic discoveries and improvements in technology, more genetic tests are made available in a clinical context than ever before. Along with this increase in genetic tests, there has been a recent rise in companies providing various genetic tests directly-to-consumers and bypassing the traditional face-to-face meeting with a health care professional. These tests offer a wide range of information regarding paternity, ancestry, health enhancement (nutrigenetics, dermatogenetics), drug response (pharmacogenetics), susceptibility testing for common complex genetic disorders, fetal gender and entire genome profiles. Direct-to-consumer (DTC) genetic tests have generated a lot of debate regarding the potential benefits and harms of this type of service. Supporters of DTC GT point to increased access for consumers and confidentiality of results (from insurance companies) as benefits. Meanwhile, detractors have many concerns, among others, regarding tests' analytical and clinical validity, as well as clinical utility; issues related to the quality of pre- and post-test counselling; and the lack of legal regulation. The issue of DTC genetic testing is particularly important to address presently, as it has direct consequences for consumers now. Both Drs Borry and Howard have earned funding (Research Fund Flanders 2008-11, and Marie Curie Fellowship 2009-11 respectively) which specifically support research in the ethical, legal, and social implications (ELSI) of direct to consumer genetic testing.

Questions to National Societies

- 1) Which companies are providing genetic tests directly to consumers in your country?
- 2) Does your country have any legislation that forbids selling genetic tests directly to consumers?