

Publication

“It’s our DNA, we deserve the right to test!” : A content analysis of a petition for the right to access direct-to-consumer genetic testing

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Aims: Various companies are currently advertising or selling genetic tests over the internet using a model of provision referred to as 'direct-to-consumer' (DTC). This commercial offer of DTC genetic testing (GT) has fueled a number of scientific, ethical and policy debates. To date there have been few studies published regarding the users' perspective. This study aimed to obtain information regarding the issues raised by individuals who signed a petition in support of DTC GT and the 'unrestricted' access to their genetic information. **Materials & methods:** We conducted qualitative content analysis of comments written by individuals who signed a public online petition initiated by DIYgenomics (CA, USA) to support "personal access to genetic information". **Results:** Of the 523 individuals who signed the petition sponsored by DIYgenomics, 247 individuals also wrote individual comments. A content analysis of these comments reveals that petitioners raised six main issues in support of unrestricted access to DTC GT: that their ownership of their DNA should allow them to have unrestricted access to their genomic information; that they should have the right to their genomic information; that the government has no place in (further) regulating DTC GT; that healthcare professionals should not be placed as intermediaries when purchasing DTC GT services; that many petitioners who had already obtained DTC GT had positive experiences with this model of provision; and that genealogy or ancestry DNA testing is one of the main activities petitioners wish to have 'unrestricted' or 'direct' access. **Conclusion:** These results give insight into why individuals may support unrestricted access to their genomic information and confirm some of the motivations of users for purchasing DTC GT. Our analysis also brings to the forefront themes that have been raised less often in empirical studies involving motivations to purchase DTC GT services; these include the strongly held beliefs of some petitioners that, since they own their DNA, they should have the right to access the information without (further) government control or physician involvement. Interestingly, the comments left by petitioners also reveal a certain distrust of governmental agencies and healthcare professionals. This urges us to further study the public's views of these services and the potential impact of these views in order to responsibly address the ongoing debate on DTC GT.

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