

e-Health and Commercial Genetic Testing

Veritas Diagnostics is a medical diagnostics company specializing in adult genetic susceptibility testing for a range of heritable and complex genetic conditions. Their main business involves testing for the mutations associated with cystic fibrosis, hereditary kidney disease, as well as breast, ovarian and colorectal cancer.

They have a well-staffed, well-run, sophisticated genetics laboratory capable of rapidly processing hundreds of samples for analysis on their many automated high-throughput DNA sequencers. Veritas considers their testing methodology to be the 'gold standard' and to that end, implement the latest testing technologies as they become available. Further, Veritas maintains good working relations with a number of leading university research laboratories, with whom they regularly verify their testing methods.

Veritas' chief clientele to date has consisted of hospitals, physicians, and private insurers ordering genetic testing for patients. The company has become known for providing quick, accurate, and confidential services at a competitive price. The Veritas Board of Directors has recently decided to expand the existing market and begin offering commercial genetic testing services direct-to-consumer through the company website.

As corporate Ethics Officer, you've been asked to work with the Vice President in charge of the new Direct-to-Consumer division to ensure that services are provided in an ethical manner. As far as the VP is concerned, the only ethical issue is consumer privacy, and given that Veritas already has privacy rules in place for dealing with physicians, hospitals, and insurance companies, the VP does not see that much needs to be changed for direct-to-consumer services.

You, however, see the situation as being more complex, and so are faced with convincing the VP that the following ethical questions must also be addressed:

1. Should Veritas Diagnostics provide in-house genetic counselling, and can this counselling be unbiased? If not, should arrangements be made with private and public genetic counselling programs, and who should pay for it?
2. Should Veritas have a formal ethics policy statement dealing specifically with issues related to marketing genetic tests directly to consumers, and should it be online?
3. What are the information privacy issues for consumers as compared with physicians or hospitals?
 - a. E.g., should 'cookies' be used on the website, to store information about potential customers? Will the information gathered be used only for improved customer service or also sold to third parties?
 - b. Who owns the genetic material used for testing - the consumer or Veritas? Can the material be sold for research purposes?
4. What limits on direct-to-consumer genetic testing are imposed by national or international regulations or oversight mechanisms ?
5. How should Veritas be working with various national health care institutions...as a contractor of services or as a competitor?
6. Will Veritas accept samples sent by employers? That is, will Veritas facilitate questionable workplace genetic testing?
7. Where can Veritas look to find 'best practices' in this area?

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The events of this case are entirely fictional; there is no "Veritas Diagnostics", and any similarity to real persons or companies is purely accidental, though hopefully instructive.

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