

“I would rather have it done by a doctor” – Laypeople's perceptions of Direct-to-Consumer Genetic Testing (DTC GT) and its ethical implications

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Background

The emergence of an online DTC GT market during the last ten years brought with it an ongoing debate about ethical implications, revolving around the right not to know, health literacy, potential harms from knowing personal genetic risk information and the question whether or not access to genetic data is a form of empowerment, among others (Covolo et al 2015).

Laws and regulations vary between different countries. While some European countries have liberal approaches to commercial genetic testing there is a restrictive framework in Germany, regulated by the genetic diagnostics act (GenDG, Borry et al 2012). However, German consumers have access to commercially offered genetic tests via internet, nonetheless.

Knowledge about awareness and perception of DTC GT among the public in some European countries already available (Vayena et al 2012; Mavroidopoulou 2015). Laypeople's perceptions in Germany are still unexplored, yet highly interesting, since the country has highly developed research and testing facilities and is a potential market for respective companies.

Aim

Extent to which laypersons' views are ethical judgements on commercial offers of medical goods

Methods

Focus Groups (n=7) with lay people (Berlin, Frankfurt, Göttingen, Köln), June – November 2016
Lay people = members of the public without academic / professional background in medicine, genetics
Participants (n=43), balanced by sociodemographic factors (3 – 9 per group)
Qualitative Content Analysis (Mayring 2007), coding with Atlas.ti

Results

Lifestyle tests and health-related genetic tests are perceived differently, the latter seen more critically. Companies are not trusted, but most participants oppose general legal restrictions.

Perception of DTC Testing Service?



F3XS(I): [...] I would do two things, definitely. [...] So just some data where I know I don't care if someone else somewhere gets their hands on them.

F13L(III): [...] I would be interested in if I am capable of doing that, it is like experimenting, right? [...], without hurrying to the doctor and listening to three words in five minutes and then sitting outside the door again.

Lifestyle test are being welcomed, health-related tests are seen as an empowering option, providing independence from doctors.

Perception of DTC GT Companies?



F19M(IV): So I would have respect for that and would think they just want to make money. [...] can also be the neighbour too, who has some sort of chemistry lab and writes down some data for me that is never really accurate, right?

F5L(I): [...] It's being played with people's fears, on purpose, especially regarding nutrition lifestyle products. And it is hard-core for profit. [...] But as I said, I principally oppose that.

Companies seen as mainly profit-oriented. They are not trusted to be legitimate businesses.

Legal Restrictions on DTC GT?



F18S (IV): But if I say now as a complete man yes I want to know it. Then it is my decision, no one is being forced to order that online. It is just an alternative to choose. It's not like doctors wouldn't be allowed to do it anymore, then.

M7S (IV): On the other hand, what does it mean, prohibiting? Prohibition leads then to the providers that have their head quarters in foreign countries.

Participants mostly opposed legal restriction of DTC GT in Germany and placed high value on the individual's right to choose.

Utility of Predictive Test Results?

Name	Confidence	Your Risk	Avg. Risk
Obesity		63,4%	63,9%
Coronary Heart Disease		50,2%	46,8%
Atrial Fibrillation		29,3%	27,2%
Psoriasis		9,9%	11,4%
Lung Cancer		6,9%	8,5%
Gallstones		6,2%	7,0%
Chronic Kidney Disease		3,4%	3,4%
Parkinson's Disease		1,7%	1,6%

M1S(I): Yes you would like to have, most of the time, some advice regarding the results so that is why you go to the doctor to get advice on what you should do with this information. With this result uhm yo, I wouldn't know right away what to do with it.

F12XS(III): I would rather have it done by a doctor. Who can directly give information and maybe explain something so that you can understand it. [...] So I would not understand so many diseases or what it is supposed to tell me exactly my risk has such a high or such a low value.

Participants prefer provision of genetic testing via doctors and put emphasis on their competence. Genetic risk information appears to be too confusing to handle on their own.

Conclusion

Laypeople in Germany have little to no awareness and of DTC GT as a consumer good. Results show an ambivalent stance:

- The wish for DTC GT as an 'empowering' option reflects how participants place a high value in autonomy, yet the understanding of genetic risk information too demanding for participants to face it on their own. There is thus a strong wish for professional counseling to compensate confusion and uncertainty, reflecting a high expectation that doctors are competent to help them.
- There is a strong distrust in commercial GT companies. Conversely, this shows trust in medical professionals and institutions and their standards, abilities and integrity. Doctor-patient relationship is strongly preferred over consumer-provider relationship when it comes to genetic testing.

The apparent trust gap has ethical implications:

- Consumerist approach to medical goods introduces element of distrust that could affect conventional doctor-patient relationship, as well. Laypeople see how medical-ethical standards of the medical profession work to their advantage by placing their autonomy and well-being first. Thus, upholding these standards reinforces the professional role of medicine. Commercial providers compete with this high standard and have to prove their trustworthiness.

References

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