

Lay Perspectives on Genomic Sequencing in Clinical and Direct-to-Consumer Contexts in Germany

Alexander Urban, M.A.; Manuel Schaper, M.A.; Dr. Sabine Wöhlke

Department for Medical Ethics and History of Medicine, University Medical Center Göttingen (Germany)

Background

Numerous quantitative socio-empirical studies show the public interest in genomic and genetic information (Bollinger et al. 2013, Vermeulen et al. 2015). Motivations include learning about own physical conditions, the possibility of disease prevention and generation of new treatment options through genetic risk information (Critchley et al. 2015). As a consequence, genomic high-throughput sequencing technologies are increasingly used beyond the traditional clinical field of application and transferred to end users through commercial application in direct-to-consumer genetic testing (DTC GT).

At the same time, the communication and interpretation of genetic information without the framing of medical expertise and doctor-patient-relationship also raise concerns and questions. While traditional medical settings seem to find more understanding and trust, there are great reservations against commercial genetic testing with respect to test validity and data security (Wilde et al 2010). However, there is a lack of empirical insight in the underlying motives and arguments of public attitudes towards these different contexts of clinical and commercial application, especially in regard to Germany.

Research Questions

- What are German laypersons' perspectives, opinions and concerns regarding new possibilities of genetic and genomic testing?
- Are there differences between attitudes towards clinical and DTC-applications? What underlying conceptions and moral arguments are framing the lay discourse?

Methods

- Qualitative design to identify differences in different application contexts of genetic testing provision
- Two focus groups (participants n=13) with lay people
- Participants mixed by age, gender and educational background
- Case vignettes for different scenarios: 1. Views on participation in clinical studies using whole-genome sequencing and attitudes; 2. Perceptions of direct-to-consumer genetic testing (part of larger study including n=6 focus groups + additional scenarios)

Preliminary Results

Clinical Context

Relativization: Trust in public vs. private research

Ms. Schmidt: The state as well as every company consists of humans able to act in any manner with any possible motivation [...]. That's why: Either I meet it with trust and do it because I think I do something good. Or I don't do it. And when I decide to do it [...] it wouldn't matter to me if it's domestic of foreign or state or in the companies, whereas the companies do research much more efficiently and faster than public institutions.

Rejection: Validity of Information

Mr. Schulze: Well there is the problem. Now I have a statistical statement and in the end I must apply it to my life or verify it. It is an impossible task to solve. That means... the complete genome analysis is giving you mock information.

Relativization: Variability of Interpretation

Mr. Schulze: The results are open to interpretation [...]. Those aren't judgements written in there [...]. Those are just options that you have. If you could have made use of them is a whole different possibility.

Direct-To-Consumer Context

Rejection: Added value of genetic risk information in DTC GT

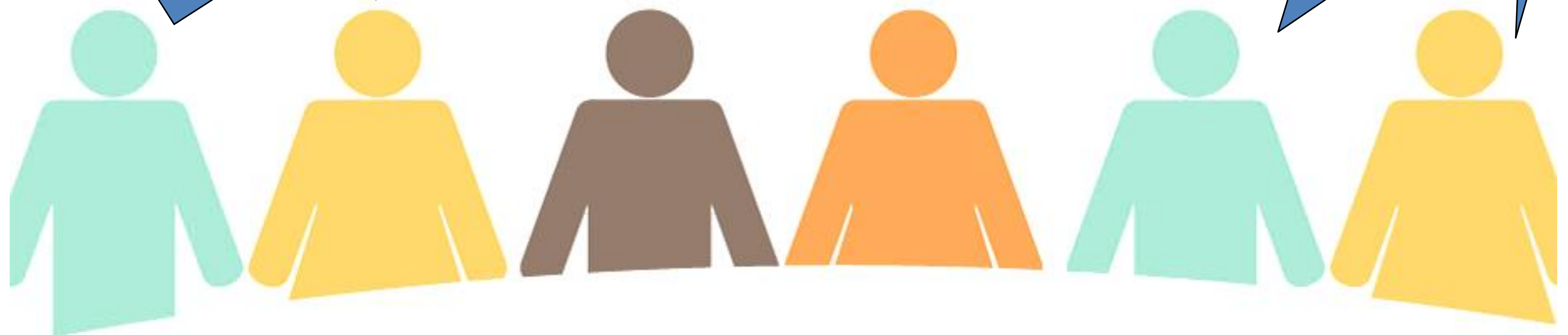
Ms. Myers: I don't see any value in these numbers. Also not in the table, nothing [...]. For me these aren't results in terms of disease that couldn't be discovered without this genetic test.

Rejection: Commercial goals undermining good intentions

Ms. Smith: But these are institutions that want to make money with this, to put it bluntly.

Framing: Self-Optimization

Ms. Johnson: I think these people are out of their mind and think about themselves a little too much. That is for people who carry a trigger on their arm and at the end of the day they check how many steps they've walked.



Summary

- Despite the ethical problems with the implementation of new genomic technologies there is personal interest in genomic information for preventive or actionable results and the self constitution.
- Participants are critical of the technology because of expectations of misuse and morally disputable actions upon genomic information (e.g. intervention in human nature).
- Beside views on commercial usage of genomic information, people try not to over-simplify moral judgements about data sharing and genomic research between public and private research institutions.
- Despite skepticism and rejection of commercial application there are positions characterized by relativizing research and data generating in different institutions. Participants doubt utility of results in both fields and reject the commercial character in DTC GT, while perceiving it as in line with the idea of self-optimization, which is implicitly framed as a negative development.

Discussion & Outlook

The results show a difference in terms of trust – participants perceive clinical and commercial application in different light, framing commercial testing as problematic due to the commercial character itself. They show little to no motivation to make use of such tests and express different positions: while they are seen as made for self-optimization, they are also perceived to lack utility. Furthermore, there are often differing perspectives within the groups: there is interest in genomic information for own good while concerns for implementation and expansion are also expressed. Further research needs to understand the contradictions in perspectives and attitudes of lay people to provide an appropriate basis for ethical reflection on the implementation of new genomic technologies and different applications in non-medical contexts.

References

- Almeling, R. & Gadarian, S.K. (2014): Public opinion on policy issues in genetics and genomics. *Genetics in Medicine: Official Journal of the American College of Medical Genetics* 16(6), 491-494.
- Bollinger, J.M., Green, RC & Kaufman, D. (2013): Attitudes about regulation among direct-to-consumer genetic testing customers. *Genetic testing and molecular biomarkers* 17(5), 424-428.
- Critchley, C., Nicol, D., Otlowski, M. & Chalmers, D. (2015): Public reaction to direct-to-consumer online genetic tests: Comparing attitudes, trust and intentions across commercial and conventional providers. *Public Understanding of Science* 24(6), 731-750.
- Vermeulen, E., Hennemann, L., van El, C. G. & Cornel, M. C. (2014): Public attitudes towards preventive genomics and personal interest in genetic testing to prevent disease: a survey study. *European Journal of Public Health* 24(5), 768-775.
- Wilde, A., Meiser, B., Mitchell, P.B. & Schofield, P.R. (2010): Public interest in predictive genetic testing, including direct-to-consumer testing, for susceptibility to major depression: preliminary findings. *European Journal of Human Genetics* 18(1), 47-51.