RISKING YOUR FUTURE

THE ETHICS OF GENETIC TESTING ON 'HEALTHY' CONSUMERS IN MODERN RISK-SOCIETY

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1 INTRODUCTION

With the rise of genetic testing[1] being offered to the general public —among others commercialised by the company 23andMe — consumers are now enabled to gain knowledge on predisposing factors that may lead to diseases (e.g. diabetes, anxiety, Parkinson's disease, Alzheimer's disease) or those relating to a healthier lifestyle (e.g. muscle composition, sleep movement, genetic weight; 23andMe, n.d.).

The most prominent criticism of this trend focuses on two things. Firstly, the unproven predictive power of genetic testing over family history or environmental factors. This characterises health to be genetically deterministic, a claim that rarely holds (Janssens et al., 2008). Secondly, the concerns regarding privacy, where genetic information may be thought of as the most personal information[2]. I will ignore these critics for the following reasons: (1) I want to provide space for ethical concerns, which I deemed implausible when regarding the epistemic concerns as well — assuming we will solve those in the future — and (2) privacy concerns merely become a problem depending on how and where they are utilised, instead of an inherent problem of genetic testing. However, these factors do play at the background of our societal context and ought not to be forgotten.

[1] In this paper I will define *genetic testing* restrictively as predictive direct-to-consumer genetic testing to improve health. I will switch the delta of genetic testing between genetic testing *as opposed to no testing* or *as opposed to clinical testing*. I believe this is intuitive, but I want to note that these differences mitigate some of the arguments discussed.

[2] Note how this concern extends beyond individual responsibility. Not only do consumers rarely read privacy policies, but by participating in these services, consumers may be exposing personal data from family members as well (Estes, 2020). This becomes especially important considering these companies use data for commercial and research purposes, opening up a whole new field of research (Chow-White et al., 2015; Hayden, 2017).

Stripping away the most prominent criticisms leaves us with three ethical concerns which I will discuss in this paper. Accordingly, there are three research questions:

RQ1 *To what extent may genetic testing provide a successful means to decrease risk?*

RQ2 *In which ways may genetic testing change an individual's behaviour?*

RQ3 *In which ways may genetic testing change an individual's identity?*

2 GENETIC TESTING AS A MEANS TO DECREASE RISK

The human tendency to define and prevent risk is a common topic in philosophical discourse. The term *risk society* stems from Beck (1992) and is extended upon by Lupton (2013). Risk society refers to a modern Western society where risk has become more pervasive, central to human subjectivity, something that can be changed through intervention and is associated with choice (Lupton, 2013, pp. 37). Note how its association with choice draws upon a neoliberal idea, which consequently assigns responsibility and blame to individuals.
Intuitively, this is exactly what genetic testing provides the public. Genetic testing draws upon discourse of neoliberalism in order to empower individuals and "live their healthiest lives" (Teladoc Health, n.d.) or "own your health" (23andMe, n.d.). For this section, we assume that people change their behaviour based on the genetic test and I will return to this assumption in Section 3.
Genetic testing is claimed to be successful along four axes: improving health, access, convenience and even privacy (Berg & Fryer-Edwards, 2008).

2.1 *Health*

The assumption is that these tests have the potential to screen people at risk and, depending on the outcome, relieve them or empower them to act upon an increased risk. Two prevalently given examples of this are the successes gained in mutations for breast or ovarian cancer and Parkinson's disease. In the case of breast or ovarian cancer, genetic tests screen for gene mutations in BRCA1 and BRCA2 (Center for Disease Control and Prevention, n.d.), which are significantly related to an increased risk of cancer (Antoniou et al., 2003). In the case of Parkinson's disease, 23andMe has published work showing two gene mutations decrease one's Parkinson's

risk (Do et al., 2011)[3]. Other studies have shown even more significant results (e.g. Alcalay et al., 2010). I will deal with these examples more explicitly in Section 3.

More often, however, genetic testing companies commercialise empowerment to change a lifestyle related to that exact same lifestyle (e.g. susceptibility to addiction) or complex diseases, which have limited clinical validity or significance (Lifestyle: Mathews et al., 2012; Diseases: McGuire & Burke, 2011; Weedon et al., 2021). Even if we take this at its best and assume these tests are valid, two criticisms still persist, namely (1) the commercial nature and (2) understandability. The United States Government Accountability Office (2010) found multiple examples of actors exaggerating the impacts of their tests to the extent that they are marketed as diagnostic tools or claiming that their supplements are able to *change DNA*. Even in the case of BRCA testing — which has clinical validity — genetic testing has been marketed to vulnerable groups with the use of anxiety-evoking strategies through misrepresentation and omission (Hull & Prasad, 2001).

Moreover, assuming a full understanding of genetic testing by consumers is rather ambitious — even though some companies do assume it (see Figure 1).

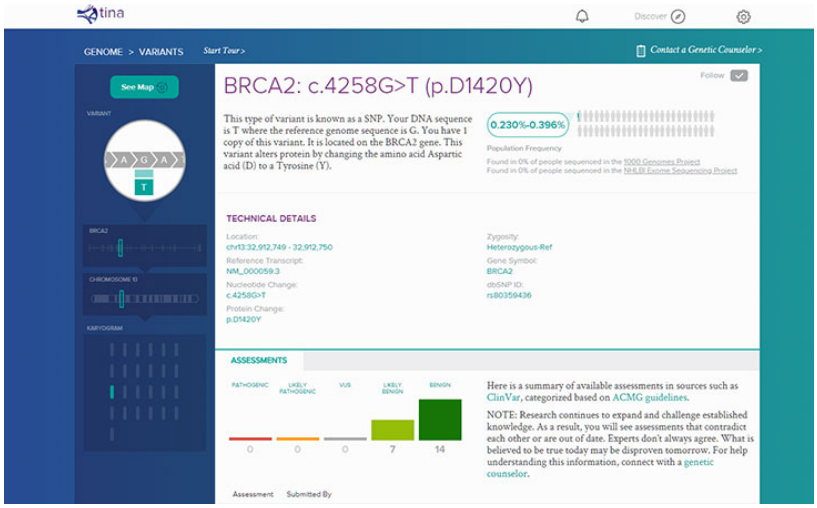

Figure 1: Representation of Genos' testing results, representing data on each variant (Hesman Saey, 2018)

Instead, companies often report on an increased or decreased relative risk, without reporting on validity (see Figure 2) and acting as a *black box*. We can question to what extent you can be empowered by these test results if you cannot interpret its information. In order for this, genetic counselling

[3] Note how genetic data is utilised by 23andMe for academic purposes. Although there are some privacy concerns associated with this practice, this also increases the window of opportunity through the use of *big data* in genomics studies.

by physicians might be necessary, which increases the workload on medical care and requires expertise physicians may not occupy (Mathews et al., 2012).
This is not just a *potential concern*, as McGuire et al. (2009) showed that 78% of people interested in such tests would ask their physician for help with interpretation. Beyond this, 61% of people even believed physicians have a *hermeneutic responsibility* towards people buying these tests (McGuire et al., 2009). This is in direct contrast with the claim that genetic testing will decrease health costs because people are more aware of higher risk and seek healthcare while it is still cheap to treat (Helgason & Stefánsson, 2010). Even if this is true, this argument works both ways — where someone may be less likely to seek health in case they have a reduced risk (McCabe & McCabe, 2004).

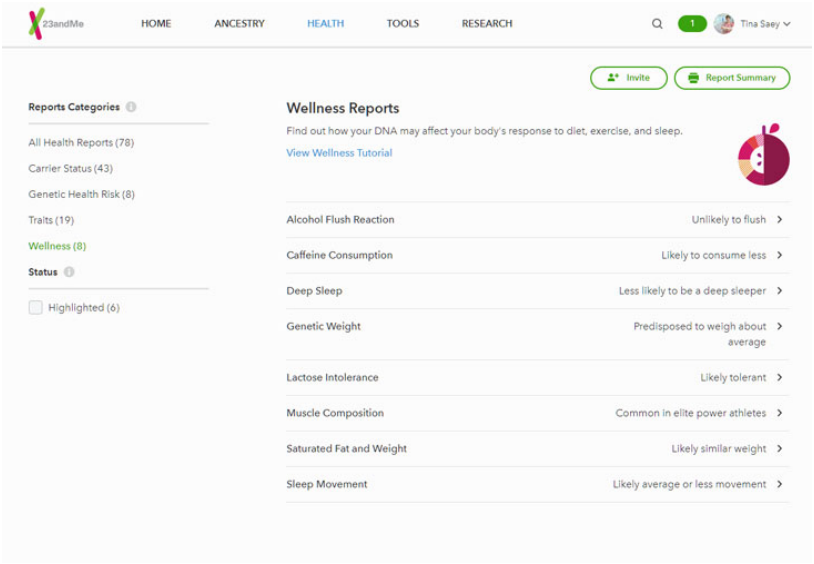

Figure 2: Representation of 23andMe's testing results, representing only relative risks (Hesman Saey, 2018)

2.2 *Access and Convenience*

Genetic testing intuitively increases access to consumers because they are provided cheaper and easier, while also skipping a physician who may be unfamiliar or unaware of some tests (Berg & Fryer-Edwards, 2008). Most fundamentally, the question would be: What information is accessed? As I have mechanised in the preceding section, the information is either simplified or hard to interpret. This already mitigates to a large extent the beneficence of better access, given that the thing to which you gain access is likely not useful.

However, nearly 90 percent of 23andMe users believe in a *right to access one's genetic information* (Gollust et al., 2017). To that end, it may not be necessary to have a use in order to believe access is a good thing. If we assume this is the case, this requires an engagement with the access and convenience arguments.

The provision of cheaper and easier services assumes that someone would have tested their DNA either way, alternatively through the clinical context. I did not find literature supporting or negating this claim, although there is criticism on whether replacement is appropriate (e.g. European Society of Human Genetics, 2010). Furthermore, companies market their services towards the general public instead of specific groups — as done in the clinical context (e.g. breast cancer screening; Lowery et al., 2008). This makes it likely that at least a portion of consumers would have refrained from testing alternatively.
Besides this, the claim that genetic testing provides cheap and easy access is true to the extent that the testing part is. However, the *easiness* advantage is mitigated when someone seeks a physician's help interpreting the results. At best the person then saves one visit. On top of this, when the person seeks such help, this also increases costs. Even though most Western states give access to primary care consultations free of charge (Boerma et al., 2015, pp. 127), these costs still come at the expense of the nation's social structure.

2.3 *Privacy*

The last claimed advantage of genetic testing is that the person does not need to involve their physician and, thereby, reduces the risk of their test results ending up at insurance companies or employers (Berg & Fryer-Edwards, 2008). In reality, however, a company will now gain access to the person's genetic information and they do not have access to better safeguards to prevent information from ending up in the exact same records, while most companies have inadequate privacy policies anyways (Reis, 2010). Accordingly, this claim is a misrepresented marketing tool instead of a genuine benefit.
Christofides and O'Doherty (2016) show consumers expect these companies to only share test results with them. These *false expectations* give a false sense of privacy, which undermines the consent given by those consumers.

3 GENETIC TESTING AND THE IMPACT ON BEHAVIOUR

Beyond the criticism of the testing itself, the fundamental assumption of empowerment is that consumers will change their behaviour based on the risk profiling received. This intuitively refers to positive lifestyle changes. Stewart et al. (2018) also report on adverse psychological responses (e.g. anxiety, distress) or health-seeking behaviour (e.g. unnecessary follow-up testing). However, they concluded there was insignificant evidence for both.

A Foucauldian analysis by Harvey (2010) showed the centrality of empowerment and health promotion in genetic testing. Building upon earlier work in nutrigenomics (Harvey, 2009), this analysis defines a *genetic entrepreneur* as someone who creates an optimally healthy future. In doing so, the individual maximises their vital capital to attain "a state of optimal wellness specific to their genetic constitution" (Harvey, 2010, pp. 371). It thus has empowering *potential*, to the extent that this person gains knowledge into possible undesirable future states and can act in order to avoid these states from happening. This is done through lifestyle changes — such as changing one's diet or quitting smoking. Note how knowledge and Foucauldian power are inherently intertwined, as knowledge increases your window of opportunity to act.

This argument assumes two things. Firstly, just because people have the potential to act does not mean they are actually acting upon the knowledge they gain. As this is the most fundamental assumption of empowerment, it is noteworthy how little evidence supports it. Given that most genetic testing offers no council, people are only told they are *at risk* without a translation to the lifestyle that ought to change. If anything, without this translation it is more likely these people become more *fatalistic* and would blame their *bad genes* instead of their behaviour (Marteau & Lerman, 2001). Moreover, a meta-analysis showed that on average less than 25% of people say they have changed their behaviour based on genetic tests, where most studies assume self-reporting was accurate and these behaviour changes lasted long-term (Stewart et al., 2018). This directly contradicts the assumption that people will act given the knowledge.

Secondly, the empowerment argument assumes that people are able to adjust their behaviour to decrease their genetic risk. However, implicit in the effectiveness of genetic testing is the extent to which risk is genetically determined (i.e. genetic tests are effective because other factors — such as lifestyle changes — have little effect on risk in the first place). This paradox is also the point where I want to bring in the previous examples of breast

or ovarian cancer and Parkinson's disease. Acting upon these risks requires rigid interventions, which looks unlikely since most behaviour changes that do happen relate to diet, exercise or vitamin intake (Egglestone et al., 2013). This leaves a person in one of two situations: (1) the person is not able or motivated to act or (2) the person is stimulated to make rigid decisions. The first already mitigates any empowerment claim to be made, while the latter may be thought of as empowering. The case of Angelina Jolie who underwent a mastectomy to decrease her risk of breast cancer gives us an example of this (Jolie, 2013). However, it is ambiguous which benefits commercial genetic testing provides us if you are ending up in the medical context for intervention anyway. Moreover, genetic tests and their interpretation can be inaccurate, specifically in the commercial context, leading to false positives and unnecessary rigid interventions. Therefore the U.S. Preventive Services Task Force classifies the process of testing and intervention for breast cancer among the general population as *potentially harmful* (Moyer, 2014).

4 GENETIC TESTING AND THE IMPACT ON IDENTITY

I subdivided this section into two parts. Firstly, I will discuss the impacts on identity in the context of testing itself (i.e. The Testers versus Non-Testers). Secondly, I will discuss the impacts on identity in the context of internalising results (i.e. Becoming Asymptomatically Ill and the Discounting Effect).

4.1 *The Testers versus Non-Testers*

Firstly, and as discussed before, genetic testing draws upon neoliberal discourse to enact autonomous subjectivity. Instead of a person receiving passive medical advice, this person seeks information themselves. Earlier in this paper, I referred to this individual as the genetic entrepreneur. Consequently, this does not only impose responsibility on those who test but also on those who did not. Whereas traditionally the welfare state has compensated for risk, now people ought to take responsibility for their own risk and are to blame if they do not (Lemke, 2004).

Secondly, genetic testing draws upon a deterministic idea of health, raising the question: Can a person be identified as *being* their genes? To the extent this is true this reinforces a sense of fatalism, even if this belief is not sharply contrasting with a belief in the efficacy of health behaviour, as suggested by Keeley et al. (2009). Fatalists, accordingly, may use genetic testing to make sense of themselves.

This exposes the difference in identity change between testers and non-testers, where testers allow the opportunity of becoming asymptomatically ill. This assumes people will genetically identify and consider this genetic risk important. They are promised certainty by genetic tests (Lemke, 2004). Therewith, genetic testing may not change behaviour regardless of the outcome, but testers are different types of people in the first place.

4.2 *Becoming Asymptomatically Ill and the Discounting Effect*

Lemke (2004) — drawing upon Foucauldian theory — argues that genetic testing has contributed to the rise of new identities. These identities belong to people that are classified as *at risk*, being coined *asymptomatically ill* or the *healthy sick*. People identify accordingly with this risk. Some literature argues genetic testing may negatively affect someone's chances in life if this information is shared with insurance companies, employers or similar actors (an overview is given in Lemke, 2004, pp. 556). I exclude this possibility in the commercial context because commercial parties have an incentive to offer services that do not negatively impact someone's health insurance or job opportunities, given that the one affected is the one paying. However, I recognise my argument assumes this sharing would be transparent.

More likely is a similarity to the asymptomatically ill with genetic diseases[4]. Klitzman (2009) showed the variability in identities among this group, where people struggle with what *being at risk* means and whether to think about themselves as *healthy*, *sick* or *predisposed/doomed*. Therefore, the answer to the impact on identity remains subjective but it is not likely to provide positive outcomes.

This is especially a problem given that the clinical validity of some genetic tests can be quite low and lead to false positives. In such cases, a person may change their self-perception and behaviour according to a high-risk outcome, while this is ungrounded and may limit their lifestyle.

On the contrary, being not at risk may also become a risk factor. Ahn and Perricone (2022) coined this as the *discounting effect* and showed how people receiving negative test results on a genetic test for alcohol abuse predisposition discounted the repercussions of that exact alcohol abuse. Accordingly, changing one's identity in accordance to test results also changes behaviour, regardless of whether the test is positive or negative.

[4] In this section, I will specifically focus on people with *high-risk outcomes* for a certain disease. I do not think that people receiving *low-risk outcomes* have no impact on identity, but I believe the focus on high-risk outcomes is more intuitive. When it comes to lifestyle factors, I will do the opposite for the same reason. Consequently, I give an example for both sides. I do not claim this analysis is exhaustive, as I think this is implausible given the space.

5 CONCLUSION

In this paper, I aimed to show the ethics and impact of genetic testing among the general population. Firstly, I discussed the claim that genetic testing is decreasing risk. Through three points I mechanised why this claim is mitigated at best: (1) focus on lifestyle factors or complex diseases are often hard to capture in risk in a meaningful way, (2) companies use false marketing and (3) genetic testing lacks interpretability. Even though access or convenience may increase, this is also mitigated when people follow up through the medical circuit.
Secondly, I discussed behavioural change opportunities for individuals. Although there are claims that genetic testing creates genetic entrepreneurship — where people act on their test results — little evidence supports this claim. At best, test results are beneficial for less than 25% of people. This still is a positive effect, which should be weighed. I, furthermore, made a case for why the discourse of genetic determinism can be harmful — even if there is clinical validity — if this reinforces rigid decisions.
Thirdly, I discussed two axes of identity. I differentiated the group testers from non-testers as having differences apriori instead of inherently changing identity, but on the other hand, I gave an analysis of how results may change one's identity regardless of a positive or negative outcome. However, the extent to which identity changes is underrepresented in scientific literature and is currently thought of as subjective. That also means there is no conclusive answer to give to RQ3.

What remains undoubted is the rise of risk society. Given this trend, it would be unsatisfying to conclude on this note. To end constructively, I would note that what we see at the core of the consumerist trend underpinning risk society is the need to gain a bigger and easier window of opportunity to improve health. I believe consumer genetic testing so far has not fulfilled that promise, and it may never do. At least this market needs more regulation regarding marketing, validity and interpretation of tests (Berg & Fryer-Edwards, 2008). Alternatively, fully integrating genetic testing within the public healthcare system may be an option — although this, pragmatically, requires a significant reduction in costs (Su, 2013).

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