Draining the Goodwill of Science
The Direct-to-Consumer Genetic Testing Industry in East Asia

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Direct-to-consumer genetics in East Asia

The direct-to-consumer (DTC) genetic testing industry is a strong example of how popular views on genetic information are intentionally exploited for commercial gain. Testing companies have emerged worldwide, and operate primarily through the internet. They typically promise convenient, accurate and professional genetic tests for personal traits and disease susceptibility. However, a recent report from the USA’s Government Accountability Office, which evaluated 15 DTC testing companies for result accuracy, consistency, confidentiality and follow-up care, casts a very negative light on their practices [1]. The report cited inconsistent test results, an incomplete data set that made inferences unrepresentative of pluralistic populations, misguided follow-up counseling and deceptive marketing practices.

Western1-based companies typically offer tests for common multifactorial diseases such as prostate cancer, breast cancer and cardiovascular disease. Eastern-based companies, on the other hand, also

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1 For sake of clarity, and to avoid lumping together different cultures, this paper refers to the USA and Western Europe as the “West” and East Asia (most notably China and Singapore) as the “East.”
offer innate talent tests. In Singapore, most DTC testing companies were active until recent years [2–4]; one company, which I will call company X, still offers its "Disease Susceptibility Gene" and "Inborn Talent" tests via its website. The homepage displays logos that "guarantee result accuracy", even though the Inborn Talent test, which claims to identify 46 talents and traits such as creativity, optimism, dancing, faithfulness and even propensity for teenage romance in young children, has no scientific evidence to support it. Quotes in general are misleading, drawing on genetic determinism:

“Smoking and drinking are risk factors but a Genetic Predisposition is the mother of all risk factors.”

A statement that is not only false, but also depreciates the influence of two important lifestyle factors that have an enormous impact on public health. Other statements draw on autonomy:

“Since knowledge is power, early identification will help you take control and maximize the development of your children.”

This statement appeals to the apparent deterministic supremacy of genetic information, and the informed, responsible parents who respond accordingly – an unrealistic ideal that was embraced even before completion of the Human Genome Project [5].

Aside concerns over the deception parents are led into, this statement is also of concern to children, who may be forced into tests and careers they do not want. A report from Singapore’s Bioethics Advisory Committee [6] expressed concerns, stating that such tests may lead to harms through the “inappropriate Genetic Testing of children or other adults without proper consent”. With potential harm to children, free access to this technology is neither ethically justifiable nor socially beneficial in the long run. A similar concern applies to tests for disease susceptibility. What are the intentions of companies such as X, or those inspected by the GAO? They are appealing to ideologies of a better health or success in the long run. A similar concern applies to tests for disease susceptibility. What are the intentions of companies such as X, or those inspected by the GAO? They are appealing to ideologies of a better health or success in the long run. A similar concern applies to tests for disease susceptibility.

Public response and consequences

So how does the public respond to this propaganda? In Asia, Singapore’s Ministry of Health urges people to be weary [4], but one satisfied Singaporean customer from DNA Matters, for example, testified that the innate talent test was accurate for his children and they indeed have the “addiction to computer games or TV” gene [3]. However, it would be difficult to find anyone who does not contain at least a small, say 10–60%, susceptibility to this trait, in a world dominated by computers, phones and TV. Driven by their desire to maximise their children’s potential to succeed in a competitive environment, parents are easily misled. At the Chongqing Children’s Palace in China, 30 children aged 3–12 years old were enrolled in a $880, five-day summer camp where they were genetically tested by a Chinese DTC testing company in order to determine their innate talents. The programme, hoping to “revolutionize child-rearing”, attracted attention from nurturing, ambitious parents who seemingly wanted nothing but the best for their children. The parents, oblivious to the lack of scientific research supporting these tests, gave positive testimonials [7]. One mother of a girl, aged just four years old, states:

“It’s better to develop her talents earlier rather than later. Now we can find when she is young, and raise her based on what her natural gifts are.”

A worrying statement that secures the concern of the BAC, since it is evident that those Chinese parents not only believe the company’s false claims, but actually strive to react to them by rearing their child according to test results.

Another worry of these ‘innate talent’ tests is their eugenic appeal. Eugenics, once popular in the West, was brought out of fashion after the Nazi’s race sterilization attempt during WWII. In the West, it is generally thought that the memory of WWII will prevent a revival of eugenics; the East, however, was less affected by this and may be more receptive to eugenic ideas. China, in particular, is no stronger to reproductive control with the one-child policy and a 1995 legislation that states Chinese couples can only marry once they pass a premartial medical examination. If the examination shows a high chance of ‘genetic diseases’ such as schizophrenia, the couple must agree on long-term contraception or sterilization before they marry [8]. This contrasts with the liberal West, and may help explain why DTC testing companies market innate talent tests only to Chinese audiences. The eugenic appeal of these tests is worrying, since history is full of examples in which sterilization, incarceration or even murder of the ‘innately inferior’ was justified on the grounds of ‘race betterment’. What people back then did not seem to realise is that eugenics has no scientific basis; traits such as intelligence and personality are complex and cannot be simply bred out, and hence the act of eugenics resembles more an act of superstition rather than racial responsibility.

Innate talent tests are therefore also an illusion, of increased success, in the same way disease susceptibility tests are an illusion of improved health; with the only difference that innate talent tests, with their eugenic appeal, also give rise to potential harms to which the public, especially in Asia, should be made aware.

Moral justification

Despite some geographical variations, the basic formula of the DTC industry remains the same: companies are appealing to social aspirations in order to gain money. In principle, their actions are morally questionable since they are knowingly engaged in deception and the propagation of false ideals as a means to an ends. The ends are no better: commercial gain that is of no interest to the well-being of others. One might argue, then, that so long as individuals are not harmed, one should have the right to use their services and to prevent this would be paternalistic. Once again, this liberal view is difficult to implement in a wider context of public health where significant harm is done not only to society as whole but also undermines the truthworthiness of science as a social and moral enterprise. Moreover, the impact on public health from genetic determinism and the DTC industry could be substantial; for example through
unnecessary spending on medicine as a result of medicalization or delayed therapy. Put together, the harm that results from the DTC industry becomes quite apparent, and this provides ethical justification for policy intervention.

The counter argument that remains is paternalism. But is the restriction of exploitative industries paternalistic or virtuous? The answer depends on one’s evaluative standpoint. Since the issue is not confined to the individual person but also pertains to public health, it can be argued that restrictions imply a responsibility over the public. However, responsibility should be proportionate in that its implementation should be through the least coercive measures possible in order to avoid excessive encroachment into individual and arguably professional autonomy. The stewardship model, outlined in a report from the Nuffield Council on Bioethics [9], is a good example of how this principle could be applied. The stewardship model stresses that there is a responsibility to “look after important needs of people both individually and collectively”. In cases like this, where the harm has a wider reach, it justifies policy interventions that act against the public vote if harm is likely to arise. This is presented as the harm principle in the stewardship model. While it is rather vague in defining what exactly constitutes harm, since the model stresses the importance of collective well-being, it clearly applies to individuals and arguably to important ethical values as well. So construed, the model fits the ideals of medical ethics as well as public health, and offers a nice compromise between beneficence and autonomy. Paternalism could be minimized through soft or non-coercive policies that maximize autonomy – for example, education, or implementing a system of corporate social responsibility in which DTC industries and the media are responsible for disseminating correct information. This is perhaps a more acceptable alternative to blunt measures such as shutting down the DTC industry – something that, in practice, would also be very difficult.

References
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