

Ethics surrounding genetic privacy in the Saudi Human Genome Project

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With the rise of AI, we are facing unprecedented rates of innovation and change. With this shift, we are compelled to consider the ethical principles that define the boundaries of our actions within the realm of AI; specifically, in the sector of genetic privacy. This paper will reflect upon the case study proposed by Stahl et al. (2022) which explores the ethical issue surrounding genetic privacy using the Saudi Human Genome Program (SHGP)-introduced by the King of Saudi Arabia in 2013. We will explore the benefits and harm of the growing rise of genetic testing understood through differing ethical frameworks. Further, analysing the role of ethical policies surrounding genetic privacy.

The SHGP, as stated by Alrefaei et al. (2022), was built upon by the citizens of Saudi Arabia and ranks as one of the top ten genomic programs in the world (p. 1). Alrefaei et al. (2022) claim that due to the “high rate of consanguinity in Saudi Arabia (SA), which exceeds 60% of total marriages, and large family sizes, SA is an in an ideal country to discover novel variants” of human genomes (p. 1). The original purpose of initiatives such as the SHGP is to collect genetic data to advance research on genetic conditions and diseases, as well as to establish comprehensive genetic databases for scientific study (Alrefaei et al., 2022, p. 1). These projects are often launched with the intention of being both beneficial and ethically sound.

Stahl et al. (2022) note that “genetic data of one person can provide information about their human heritage” (p. 1). This capability can unveil genetic mysteries that might have otherwise remain hidden, often prompting ethical questions about how such information is owned, used, and stored. A recent example is the company 23andMe, which made headlines following its bankruptcy. Interestingly, Stahl et al. (2022) seemed to anticipate such developments by highlighting the uncertainty surrounding the ethical policies of private companies in face of bankruptcy.

Data privacy becomes crucial when personal details of consumers become involved. Leaks can often prove harmful to not only the individual, but families as well. Stalh et al. (2022) argue this can take the form of revealing hidden family relations (p.1) (ex. false biological relations) that people have fought to protect. This ethical dilemma raises the question of whether biological identity should be transparent regardless of the circumstance. In their paper, Stalh et al. (2022) deem the revelation of such hidden relations a negative consequence, especially for those who's family legitimacy represents the position they hold (ie. rulers, or inheritance matters). Most individuals participating in such projects are often looking for the truth of their genetic makeup. Disclosure of that information should remain that individual's right. On the other hand, viewing this considering the principal of relativism, we can argue that biological legitimacy remains a public issue, especially when it concerned public figures who benefit from claiming false heredity. What one person deems ethical may be different from the other in this relativistic lens.

The ability to predict disease to the level of depth projects such as the SHGP provide can prove to be negatively consequential to people who are not equipped to face difficult decisions regarding their health (Stalh et al., 2022, p. 2). What begins as a natural curiosity to learn more about oneself can quickly take an unsettling turn when a consumer discovers distressing health information-such as the presence of an incurable genetic condition. This can lead to irreparable damage if the patient takes any actions based upon false positives (ie. tests showing a person has the disease when in fact they do not).

Stahl et al. (2022) express the ethical concerns of such cases, arguing that while the patient is at minimum provided with the data, the companies are left to reap the benefits (p. 2). This high level of medical information can also prove negative when the patient is not educated in the technical insights provided by the genetic services. Alrefaei et al. (2022) concluded a "moderate

awareness and attitude towards the SHGP ... [and a] low level of knowledge” on the data privacy of such a project (p. 8). This questions the ethics surrounding initiatives such as the SHGP. If a person cannot grasp the extent to which their data can be used, and further the risks of a data breach, how can the initiative remain ethical? Furthermore, should the person be able to have full access to the records regardless of medical knowledge that would prevent them from drawing false conclusions?

In the lens of the principle of contractualism, the SHGP raises serious concerns. If participants are not fully aware of what they are agreeing to, can we really claim they have given informed consent? This represents a flawed contract and cannot argue the ethical nature simply because a person has agreed-especially someone who has not grasped the risks. Similarly, using a Kantian framework pushes us to think about how people are treated throughout this process. Kantianism states we should never treat someone as a means to an end. If initiatives like the SHGP lead to companies profiting from data that participants do not fully realize they are surrendering, or if individuals are left to face complex medical decisions without adequate support, then it is clear that we are falling short of ethical standards.

Another concern highlighted by Stalh et al.(2022) is mission creep-“when the original purpose of the data collection is replaced by a changing or altogether different use” (p. 2). The SHGP was originally introduced to improve understanding and treatment of inherited genetic disorders; however, as Stalh et al.(2022) point out, the broad scop of data collection and lack of clear boundaries raise the risk of the data being repurposed for unintended uses. These uses can take the form of law enforcement tracking, population surveillance and can result in discrimination due to genetics. The issue here is not just about how the data is used, but whether if participants were informed of the potential of secondary uses. This reflects Price and Roche’s (2014)

concerns around gaps in legal protections-particularly outside the USA where frameworks like GINA offer only partial coverage, mostly limited to health insurance and employment. If the goals of the SHGP evolve overtime without corresponding updates to consent forms or participant agreements, then the ethical legitimacy of the project is undermined.

To reduce harm and avoid future ethical dilemmas, we need stronger privacy protections. Aziz et al. (2017) outline several technical methods that can help. These include homomorphic encryption, which lets researchers run computations on encrypted data-meaning the data remains private even during analysis (Aziz et al., 2017, p. 4). Beyond the technical protections we must ensure holistic solutions for all participants, ensuring they are fully educated in the consequences, and pathways of support for participating in projects such as the SHGP.

The SHGP is a great example of the ethical nature of human genetic projects. Although the project was created to uncover the biological mysteries surrounding human genetics, the lack of clear privacy, protections, informed consent, and long-term data policies makes it ethically unclear. Through the frameworks of relativism, Kantianism, and contractualism, we can see the various ways these issues impact individuals and society. Ethical frameworks are helpful because they remind us that good intentions are not enough. As we move forward with powerful projects such as the SHGP, we must constantly re-evaluate the processes; only then can these projects live up to their promise without crossing ethical lines.

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