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Ethical Issues in DNA Fingerprinting: Privacy, Consent, and Data Protection

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Abstract

DNA Fingerprinting, which is also known as DNA Profiling, is one of the more important scientific discoveries of the present age. Since its discovery in 1984 by Sir Alec Jeffreys, the DNA fingerprinting technique has altered forensic sciences and the medial diagnosis field which changed the outlook of human identity. While there have been very real benefits of technology, such as in criminal justice, healthcare, and ancestry research, increasing scientific benefit comes with complex ethical issues. Genetic information can reveal a wide array of information about a person beyond their identity, family ties, hereditary diseases, or risks of developing a disease or becoming ill.

The ethical issues concerning DNA fingerprinting are privacy, informed consent, ownership of information, discrimination, and misuse. This study examines previous literature and affordability survey results with 136 respondents regarding the awareness, attitude, and concerns of fingerprinting and DNA fingerprinting. Findings show that the people do not realise the ethical risks of DNA fingerprinting although level of awareness is high; hence, need for stronger law with more transparency and public education. A multi-dimensional ethical framework is advocated to address the use of genetic data. The analysis further deliberates the social, legal and psychological aspects of genetic data.

Introduction

These are sequences of DNA that are unique to every individual and can be used for identification purposes. Sir Alec Jeffreys invented this in 1984, which changed the face of forensic science and human genetics. Originally designed to help solve crime and family disputes, it quickly encompassed parentage testing, immigration, and medical studies, and, more recently, commercial genetic testing services. DNA tests are now available to everyone, especially with the commercial testing kits. It’s more accessible than ever before and not just in laboratories or courts.

Due to the rapid spread of DNA technology, there is widespread debate over its ethical ramifications. Other forms of an individual’s personal information can be changed but not the DNA. It is a permanent and uniquely identifying characteristic, which has linkage to personal identity and biological heritage. The threats posed by powerful include invasion of privacy, misuse of sensitive data, lack of informed consent, confusion over the ownership of genetic material and potential for genetic discrimination. The growing risk is enhanced by the enormous amounts of data being collected, from the large forensic public databases of governments to private direct-to-consumer genetic testing companies. Because of all the accumulated information, the resource can now seem “rich” and interconnected, and therefore valuable for research and law enforcement purposes but extremely vulnerable to breaches, re-identification and unethical secondary uses. The research paper studies some of the ethical issues and analyses public understanding through the survey data collected from a total sample comprising 136 samples. Thus, it presents a complete analysis of the ethical dimension of DNA profiling.

SCIENTIFIC BASIS OF DNA FINGERPRINTING

DNA fingerprinting works by exploiting regions of DNA known as short tandem repeats. These are sequences of genetic code repeated over and over that differ greatly between different individuals and can, therefore, be used to identify an individual. Testing involves the collection of blood, saliva, skin cells, or hair follicles. The samples obtained are then amplified using a novel technique called polymerase chain reaction, whereby millions of copies are made from a particular DNA sequence, analysed to produce a genetic profile. This resulting profile is, in essence, just a numerical profile revealing the lengths of the STR fragments, not a detailed map of the complete genome.

The DNA profile obtained from a sample is then matched against known reference samples from a crime scene, medical history, relatives, or any accessible genetic databases. Further, because of its mostly high accuracy-as these usually feature astronomically low probabilities of a random match-it has also often been considered one of the most reliable methods of identification in humans. Again, these does not rule out laboratory errors, sample contamination especially in evidence traces, and subjective analysis of complicated multiple mixtures. These limitations pose a number of serious ethical

Methodology: Surveys to establish public perception

Data from the literature that was collected qualitatively was put together with data that was collected quantitively on the awareness of the public. One hundred thirty-six subjects (ages 18 years to 75 years) from all educational and social strata were asked to answer a structured questionnaire containing 12 questions. The sample selection was to be broadly representative of public consciousness on matters relating to DNA technology but not too strictly so. The “DNA Fingerprinting” questionnaire sought to measure awareness, assessments of ethical risks, trust in the public and commercial institutions responsible for DNA fingerprinting, attitudes toward genetic privacy, and possible regulations.

The survey contains questions with closed -end questions like the Yes/No, Multiple Choice as well a Likert scale to measure factual knowledge along with an opinion. The informed consent was based on the voluntary condition and complete anonymity of the study participation. No privacy information nor real genetic data was collected. The data was analysed with the help of descriptive statistical tools which involved percentage distribution, a cross-tabulation which is a comparison of awareness levels vis-a-vis demographic factors and a comparative analysis of the expressed concerns. Research procedures were ensured to be harmless to participants. They also ensured the confidentiality of research data.

Results: Public Awareness and Ethical Gaps

These survey responses provide evidence of a broadly general understanding of the technology, which is consistent with the technology's integration into the public discourse. 85 percent of the respondents demonstrated knowledge of DNA fingerprinting and its use in forensic science and other medical applications. Such a high number points to the fact that media coverage and educational campaigns have been very successful in imparting basic factual knowledge.

Privacy Literacy Gap:Just 42 percent of the overall respondents were able to correctly explain the situation where DNA privacy could be violated through a highly advanced method, such as re-identification from anonymised datasets, data breach, or most significantly, secondary use by third-party organisations or law enforcement which is more commonly known as 'function creep'.Trust Disparity: While 78 percent of interviewees said they would trust DNA technology if a nonprofit medical research institution performed the related activities, only 34 percent of the same group trusted a commercial, for-profit genetic testing company with this kind of sensitive information - a big public trust issue for the commercial sector.

One of the conditions for direct-to-consumer genetic testing companies, such as those providing ancestry or wellness reports, is that they are based on consumer contracts that are complicated, legalistic, and complex in terms and conditions. The small print permits the company to have an almost unlimited amount of time with the storing of the genetic sample and derived data; it can be for decades or even indefinitely, and the company can share it, sell it, or grant a license to any third-party actor, such as a pharmaceutical company, academic researcher, or the police department, law enforcement, or other government agency. Most people just tick the "I Agree" box in a hurry, eager to get their results, and without fully understanding that their DNA might be stored for a long time, shared with foreign countries, or used for other purposes than the ones for which they got tested in the first place. This kind of behavior undermines the core ethical principle of informed consent - the one which states that informed consent must be voluntary, ongoing, and based on a clear understanding of risks and benefits - and it gives commercial entities controlled by profit motives rather than the individual the power and control over the situation.

The possibility of genetic discrimination is ranked among the most dreaded ethical risks, and this is supported by the survey data as well. The respondents to the survey define discrimination as a scenario in which a person is subjected to unfair treatment because of their genetically determined or genetically related condition, whether the latter is real or only perceived. Discrimination can be limited to the insurance industry in which health companies may deny cover or increase premium rates on the basis of susceptibility to a certain chronic disease and at the same time employers reject or not promote the candidate who carries a gene variant that points to a future health risk. However, despite the existence of GINA and other laws in the US that regulate health insurance and employment and that offer some protection, loopholes still exist. For instance, GINA does not cover long-term care, life, or disability insurance. In addition, discrimination may extend from institutional to social stigma whereby individuals are labelled or judged because of their genetic 'defects' or predispositions which eventually leads to psychological distress and social exclusion. The ability to foresee an individual's future health puts institutions in a position where there is a moral hazard and thus they can be allowed to manage the risk pre-emptively albeit at the expense of the individual's rights.

Social and Psychological Impacts

DNA fingerprinting is also often poorly addressed on emotional and social issues, in addition to the legal and ethical issues. Ancestry or paternity testing results can disrupt lives deeply. The identification of new half-siblings, non-paternity events, or entirely new ethnicities can conflict with one’s narrative about their identity, heritage, and family, thereby resulting in family disruption and psychological harm.

- Most of the countries has forensic regulations, with forensic DNA databases that are hosted at a government level such as UK National DNA Database and US CODIS. Legislation usually governs the conditions of entry and retention time-whether for instance the DNA of unconvicted arrestees can be retained-(and how access is controlled).

Case Studies: Lessons from Real-World Application

Real-life cases have powerfully illustrated how DNA fingerprinting ethical dilemmas unfold.

Data Sharing by DTC Companies: Many commercial genetic testing companies have either faced court action or public condemnation for sharing data with third parties, big pharmaceutical companies among them, in most cases without clearly explicit consent beyond an agreement form. Take the deal between the DTC company 23andMe and GlaxoSmithKline as proof of the enormous corporate value of such data. It has proved the public's fear that personal genetic information is being commodified in order to advance corporate interests without equitably sharing it with them. High-profile data breaches, such as one involving the testing company Vita-gene, which exposed millions of genetic records, give credence to digital genetic infrastructure fragility and catastrophic consequences of failure.

Informed by these findings, and significant ethical literacy gaps identified from the literature review, this study calls for a three-pronged governance strategy of increased legal protection, transparency in data practices, and public education.

1. Enhance Legal and Governance Frameworks:

The retention limits across state and commercial databases should be regulated by fully independent, well-funded bodies with powers of audit over genetic data practices and the potential to invoke serious sanctions should misuse occur.

- Specific Protections against Discrimination: Percy would close current loopholes in the law that permit genetic discrimination in life, disability, and long-term care insurance.
- Security Standards: Facilities in which this genetic data is stored should be mandated to implement state-of-the-art, tamper-proof cybersecurity mechanisms. These need to include zero-trust architectures, standards for encryption that meet but preferably outstrip the current governmental security classification, among other such measures.
- Inclusion of Genetic Literacy in the Curriculum: Modules of Genetic Literacy must be part of the education systems from high school to later university years. The syllabus would include the science of DNA profiling, the rights pertaining to genetic data like GINA and GDPR rights, the dangers of commercial tests, and importantly, ethical data sharing with relatives.

Future Scope

- Gene Editing and Profiling: Consider the ethical rules that govern the use of very complex methods such as WGS and the ethical restrictions that gene editing - for example, CRISPR - which changes the genetic code by altering, not merely describing, should have.
- Global DNA Databases: Consider the ethical and legal issues involved in the creation and existence of global, interconnected DNA databases that, while helpful in the detection of transnational crime, would raise significant concerns about human rights and sovereignty.
- Long-term Psychological and Social Studies: There is a need for long-term, longitudinal studies to understand public attitudes, individual behaviours, and familial relationships as genetic technologies become more prevalent, more powerful, and more integrated into daily life.

Conclusion

DNA fingerprinting is a powerful scientific tool that has great potential in law enforcement, healthcare, and personal discovery. It has served as a cornerstone of justice and a catalyst of medical advancement. To date, however, its power is equaled only by the gravitas of the serious ethical challenges it elicits, which cannot be left unconsidered in an increasingly digital data-dependent world. Privacy, genuine informed consent, fair ownership of genetic material, potential misuse, and rampant fear about genetic discrimination remain areas of heightened concern. This research uncovers that while general awareness of DNA fingerprinting is high, ethical understanding-that is, knowledge to make truly autonomous decisions-remains low. Fear of misuse and discrimination among the public is extremely high and requires a positive, proactive response from policy thinkers on all fronts. Second, strengthening legal frameworks is needed, as well as the enforcement of mandatory transparency by custodians of data. Third, ethical and genetic literacy within the general population is also an essential requirement. Only through such robust, ethical governance models will genetic technologies be used responsibly, ethically, and for the enduring benefit of humankind, rather than being used as tools of surveillance or exploitation.

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