International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

Strengthening India's Genomic Data Security

Leona Tom

Student, School of Legal Studies, REVA University

Abstract:
The rapid growth and development toward providing and ensuring better health to individuals is very evident with the availability of its required technological advancements and resources. Genomic data, derived through such advancements, is a significant contributing factor which would aid in promoting public health. In this age of digitalization, every individual is exposed to an unforeseen situation where their personal data or information may at any moment be found and misused for no good reason. Ever since the usage of genomic data to help mitigate diseases in human beings, a rapid growth has been seen in its usage. In India, the first genome sequencing was done in the year 2009 and has recently collected over 10,000 genomes. This has surely contributed to the wellness of the population and acceleration of research and shall in the future be used to an even greater extent. Along with its strikingly indispensable growth, there is as much requirement for a legal framework to facilitate its growth without any barriers and at the same time keeping in mind the need to protect the data from unauthorized usage and to also keep the same confidential enough to terminate any discrimination of the patient or say, whosoever the genome data belongs to. This paper attempts to put forward the current dangers relating to genomic data protection, which include discrimination based on genomic data of a person, misuse of such data and finally, the manner of governance of sample sequencing conducted abroad. Due to the inadequacy of laws in India for the protection of a person's genomic data, it is of great necessity to establish a legal framework to protect and ensure the authorised use of the same. This paper also attempts to put forward certain exercises or say, steps taken by different countries like the United Kingdom, whose legal system is very similar to that of India's and also possessing data protection legislations to govern and ensure the safety of genomic data and other countries such as Switzerland and the United States for the purpose of creating a stronger legal framework to ensure the security of such sensitive data.

Keywords: Genomic Data, Data Privacy, Regulations.

Introduction

The world today, has reached an impressive extent in its technological advancements and continues to experience rapid growth in that regard. While this is necessary, there is a concurrent need, a requirement for the control and regulation of the same due to the associated risks. Focusing on the current dangers coming with the use of genomic data in India, this paper seeks to highlight the risks related to such data and the regulations adopted by various countries to eradicate such risks. The first genome sequencing in India was announced in the year 2009 and the sequencing of over 10,000 genomes has been completed by the GenomeIndia project funded by the Department of Biotechnology, Government of India, recently[1]. This is a major accomplishment for India. However, while it represents most of the genetic constitution of

[1] What is GenomeIndia? *available at*: https://genomeindia.in/index.php (last visited on May 20, 2024)

the country's diversity, the use of genomic data also carries certain challenges that need to be addressed with an appropriate legal framework to protect and secure such data from malicious intent.

Before delving into the mentioned issue, it is necessary to address what the terms mean. Deoxyribonucleic acid (DNA) is the molecule that carries genetic information for the development and functioning of an organism[2]. While DNA is the information molecule for all organisms, the entire set of DNA instructions found within the cell of an organism is called its Genome[3]. Genomics studies all the genes of an organism, their genome, to find every difference, no matter how minute, contributing to a specific characteristic and is also a young field that relies on advancing technology stepping in to provide solutions when genetics is just not helpful enough[4]. Hence, data derived from the genome is referred to as genomic data. It is indisputably different for each individual and exposes the probability of diseases, ancestry, ethnicity and such of an individual and may be construed as that individual's personal information. India currently does not possess an exclusive data protection legislation focusing on such sensitive data of an individual. However, the Digital Personal Data Protection legislation enacted in the year 2023 has not yet come into force but defines an individual's personal data as- "personal data" means any data about an individual who is identifiable by or in relation to such data[5]. Although the genomic data of an individual is made anonymous, there are chances of its reidentification which poses danger to whoever the data belongs. Therefore, such data may come within the ambit of the aforesaid definition.

While society benefits from utilising such data in the areas of personalised medications, disease predictions, research and so on, the current dangers related to this data ("genomic data", "genetic data" hereinafter addressed as "data") in a general sense include data privacy issues primarily due to its sensitive nature, ethical challenges involving unforeseen health conditions and consent of the data subject, discrimination based on such data in areas of employment and insurance, and challenges regarding the accessibility of such data. In India, the major challenges arising from such data include the manner of governance of sample sequencing conducted by companies abroad, discrimination based on genetic information and the misuse of such data, upon which this paper aims to highlight and discuss the related legal frameworks adopted in countries abroad [6]. The challenges associated with such data worldwide, as well as in India, will be discussed. Countries worldwide have formulated specific regulations to monitor and regulate issues due to the sensitivity of the information. The United States of America, Switzerland, and other countries and as well as the European Union, and such organizations, have formulated frameworks such as the Genetic Information Non-Discrimination Act 2008, Human Genetic Testing Act 2004, the General Data Protection Regulation 2018 (GDPR) and so on, which will be discussed in detail. With the Brexit[7] of the United Kingdom from the EU, the UK is no more a part of it but has retained in its domestic laws, the UK GDPR[8]. Therefore, the GDPR will be taken for discussion. The purpose behind

[2] National Human Genome Research Institute, USA, *available at*: https://www.genome.gov/genetics-glossary/Deoxyribonucleic-Acid (last visited on May 28, 2024)
[3] National Human Genome Research Institute, USA, *available at*: https://www.genome.gov/genetics-glossary/Genome (last visited on May 28,2024)
[4] The Jackson Laboratory, USA, *available at*: https://www.jax.org/news-and-insights/minute-to-understanding/genetics-vs-genomics# (last visited on May 28,2024)
[5] The Digital Personal Data Protection Act, 2023 (No. 22 of 2023), s. 2(t).
[6] Vinod Scaria, "Why India urgently needs a legal framework for genomics" *The Hindu,* Mar. 9, 2024.
[7] Brexit: the UK has officially left the EU- what happens next?, *available at*: https://www.bbc.com/news/world-europe-51307874 (last visited on May 29, 2024)
[8] Information commissioner's office, the UK GDPR, *available at*: https://ico.org.uk/for-organisations/data-protection-and-the-eu/data-protection-and-the-eu-in-detail/the-uk-gdpr/ (last visited on May 29, 2024)

mentioning the laws adopted by these countries and organizations worldwide is to favour the framing of laws for the protection of sensitive data in India for promoting the enhancement of its security and assurance of the privacy of individuals.

The Pros and Cons of Genomic Information

With the emergence of the technological advancements favouring the collection of genomic data, the world has seen recognizable improvements in the field of research and medicine evidently. This statement may be supported by literature review of previous papers that deal with the usage of genomic data. From a worldwide point of view, firstly, in Northern Portugal, a cross-sectional study compared the views of a number of rare disease-affected patients, informal carers and healthcare professionals about the benefits and risks of sharing genomic data for research and factors associated, found that the use of genomic data benefits the discovery of a cure for untreatable diseases and the development of new drugs and treatments[9]. Secondly, in a research based in the United Kingdom, China, United States of America, Canada and Australia, combining genomic data and routinely collected health data was said to favour the prediction of genetic risk factors for diseases, levels of gene expression, and social and behavioural characteristics such as educational attainment, impulsivity and recreational drug experimentation[10]. In India, genetic tests estimate the lifetime risk of disease, predisposition to certain traits, and response to drugs, aiming to guide strategies to reduce disease risk and manage health. They also identify the molecular cause of existing diseases[11]. Genomic data influences the world in many other ways including cancer treatments, pharmacogenomics and so on[12].

Moving on to the risks, or say, issues related to such data, in the previously mentioned study conducted in Northern Portugal, a lack of security and control over information access and the extraction of information exceeding research objectives was the main concern of patients and carers, while the professionals were concerned with the discrimination of citizens caused as well as with extraction exceeding research objectives. The research based in the five countries that included the United Kingdom, China, United States of America, Canada and Australia, mentioned that the challenges that come along with the combination of genomic and routine data were- data collection, data storage and costs, technical and/or software issues, and data privacy and data protection laws.

Current Concerns Related to Such Data in India

The global influence of genomic data highlights its significance for both the present and the future. While the concerns about the security of such data persist worldwide, India needs an adequate framework to address its current concerns at the very least.

Regarding the manner of governance of sample sequencing/analyzation conducted by companies abroad, human biological samples for commercial purposes are to be exported as per the notification issued by the

[9] Mariana Amorim, Susana Silva, *et.al*., "Benefits and Risks of Sharing Genomic Data for Research: Comparing the Views of Rare Disease Patients, Informal Carers and Healthcare Professionals" 19 *International Journal of Environmental Research and Public Health* (2022).

[10] Daniels H, Jones KH, *et.al*., "Exploring the Use of Genomic and Routinely Collected Data: Narrative Literature Review and Interview Study" 23 *Journal of Medical Internet Research* (2021).

[11] Pemmasani SK, Raman R, *et.al*., "A Review on the Challenges in Indian Genomics Research for Variant Identification and Interpretation" 11 *Frontiers in Genetics* (2020).

[12] National Human Genome Research Institute, USA, *available at*: https://www.genome.gov/dna-day/15-ways (last visited on May 19, 2024)

Directorate General of Foreign Trade[13]. While clearances from the Health Ministry Steering Committee are required for research collaborations, the Director General of Foreign Trade notification enables samples abroad for commercial purposes and this has been exploited by large pharmaceutical and research organisations abroad to conduct research on Indian samples despite the availability of the required expertise in India, these samples are sequenced with little oversight and regulation[14]. The export of human biological samples has been controlled by the relevant authorities mentioned in the Export Policy of schedule II, chapter 30 of the Indian Trade Classification (Harmonised System), 2018. It allows the export of these samples subject to the policy conditions mentioned in chapter 30. As per the notification no. 19/2015-2020 regarding amendment in the import/export policy for human biological samples for commercial purposes, customs authorities are also supposed to permit the export or import of these samples without prior approvals from any other government agency, provided that the concerned Indian company or agency submits an undertaking stating that the applicable requirements for the safe transfer and disposal of the samples are followed[15]. However, these regulations do not seem do impose any conditions over the recipient of the samples. This needs to be regulated to secure the interest of the data subjects and the data itself.

The challenge of discrimination based on genomic data is also a concern in India. This discrimination may be evident in the fields of employment and insurance. In a High Court of Delhi case, 2018, the Court highlighted that the exclusion of genetic disorders is not only a contractual issue but also impacts the boarder canvas of the right to health in the context of providing insurance and directed the Insurance Regulatory and Development Authority of India to examine the exclusionary clauses in insurance contracts and ensure that insurance companies do not reject claims based on exclusions related to genetic disorders[16]. However, the Supreme Court of India, put a stay on the operation of the judgement of the High Court. The Indian Council of Medical Research has laid down the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 which mentions that there is a likelihood of social stigmatization as well as discrimination in areas of schooling, employment, health and general insurance which requires ample care[17]. It is thus necessary to create a framework addressing such discrimination.

The risks of genomic data misuse also need to be investigated. While ensuring the ethical use of such data, it is necessary to mitigate or, at least, minimize its misuse. The misuse of this data can lead to privacy breaches and could also include the previously discussed risks concerning India. The right to privacy is a constitutionally protected right[18] of an individual emerging from the guarantee of life and personal liberty in art. 21[19].There is a need for adequate guidelines to ensure the secure and ethical use of such data. The guidelines formulated by the Indian Council of Medical Research, however, do not legally bind the scientific community[20].

[13] Indian Council of Medical Research, India, *available at*: https://main.icmr.nic.in/content/transfer-biological-material (last visited on May 20, 2024).
[14] Vinod Scaria, "Why India urgently needs a legal framework for genomics" *The Hindu,* Mar. 9, 2024.
[15] Import/export policy for Human Biological Samples for commercial purposes: amendment Schedule - 1 (Import Policy) and Schedule - 2 (Export Policy) of ITC (HS), 2012, *available at*: https://content.dgft.gov.in/Website/noti1916.pdf (last visited on May 19, 2024).
[16] *United India Insurance Co. Ltd. v. Jay Prakash Tayal* (2020) 15 SCC 115.
[17] National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017, *available at*: https://ethics.ncdirindia.org//asset/pdf/ICMR_National_Ethical_Guidelines.pdf (last visited May 19, 2024)
[18] *Justice K.S Puttaswamy(retd) v. Union of India* (2019) 1 SCC 1.
[19] The Constitution of India. art. 21.
[20] Hannah Kim, Calvin W. L. Ho, *et.al*., "Genetic Discrimination: Introducing the Asian Perspective to the Debate" 6 *NPJ Genomic Medicine* (2021).

Laws, Guidelines Adopted by Countries and Organizations Abroad

In bringing attention to the concerns of India regarding genomic data, it is also necessary to mention the related frameworks, laws and guidelines laid down by countries and organisations abroad.

The Global Alliance for Genomics and Health (GA4GH) is a not-for-profit alliance that sets technical standards and frames policies and tools promoting the expansion of responsible, voluntary and secure use of genomic data and other health related data within a human rights framework[21]. It works on building on the Framework for Responsible Sharing of Genomic and Health Related Data, intended for all entities or individuals involved with genomic and health-related data, including data donors, users, producers, researchers, research participants, patient communities, publishers, funding agencies, data protection authorities, hospitals, ethics committees, industry, health ministries, and public health organizations[22]. The GA4GH Regulatory and Ethics Toolkit includes components such as Model Consent Clauses that may be used to assist researchers in drafting interoperable consent forms, and Machine-Readable Consent Guidance (MRCG), which aims to permit researchers to search for datasets that have been consented for their research purposes[23]. Although these tools seem unavailable, the implementation of such idea would be beneficial.

The United States of America formulated the Genetic Information Non-Discrimination Act (GINA) of 2008, consisting of provisions for the prevention of discrimination based on genetic information in the areas of employment and health insurance. Title 1 of GINA deals with discrimination in health insurance for which the Departments of Labour, Health and Human Services and the Treasury have responsibility for formulating regulations and title 2 consists of provisions regarding the prohibition of employment discrimination based on genetic information[24]. The term "genetic information"[25] is defined and excludes from it the information relating to the sex or age of an individual. The sections[26] state the practices by the employer, employment agencies, labour organisations as well as training programs, regarding such information. They prohibit the discrimination of employees or individuals with respect to such information in hiring, discharge, compensation, terms, conditions, and employment privileges[27]. They also prohibit segregation, limits or deprival, or other actions that would adversely affect the status of the individual, employee or member[28]. Exceptions[29] to such discrimination haven been laid down, which include- receiving of test results only by the concerned individual and the licensed health care professional or board certified genetic counsellor involved in providing such services, such information can be available to the mentioned entities in aggregate terms that do not disclose the individual's identity, inadvertently requiring such information, providing wellness programs, and the individual's written authorization, among others mentioned therein. It also specifies that such information shall be maintained on separate forms and

[21] Global Alliance for Genomics and Health, *available at*: https://www.ga4gh.org/about-us/ (last visited may 19, 2024)
[22] Framework for Responsible Sharing of Genomic and Health-Related Data, *available at*: https://www.ga4gh.org/document/framework-for-responsible-sharing-of-genomic-and-health-related-data-sharing-v1/ (last visited on May 19, 2024)
[23] Heidi L. Rehm, Angela J.H. Page, *et.al*., "GA4GH: International Policies and Standards for Data Sharing Across Genomic Research and Healthcare" 1 *Cell Genomics* (2021).
[24] Genetic Information Non-Discrimination Act, USA, *available at*: https://www.eeoc.gov/statutes/genetic-information-nondiscrimination-act-2008 (last visited on May 29, 2024)
[25] *Id.*, s. 201 cl. 4.
[26] Genetic Information Non-Discrimination Act, 2008, ss. 202, 203, 204, 205.
[27] *Ibid.*
[28] *Ibid.*
[29] *Ibid.*

medical files and is to be treated as a confidential medical record of the employee or member[30]. The limitations as to disclosure are also specified with exceptions under s. 206(b)[31]. It also covers remedies[32] which may be provided according to the laws under which the employees are covered. The laid provisions can be favourable in the creation of a legal framework that addresses genetic discrimination.

The Human Genetic Testing Act (HGTA), 2004[33], of Switzerland, in its status as of 2007, stipulates the conditions[34] under which human genetic testing may be performed in medical, employment, and insurance contexts, as well as in the determination of liability. Specifically, in the contexts of insurance[35] and employment[36], it prohibits requiring presymptomatic genetic tests[37] and, in the case of insurance[38], prohibits prenatal genetic tests[39] as well. Art 22 of the Act[40] provides exceptions for conducting presymptomatic tests at hiring and during professional relationships to prevent occupational diseases or accidents. The exceptions focus on preventing any occupational diseases or contamination and checks for any signs of the same. Art. 23[41] and 24[42] state that the test must address only the predisposition that is relevant to the particular post in employment and requires providing genetic counselling as well and the sample used for the test needs to be destroyed upon completion of the test. The results are to be revealed only to the person whose test was conducted, and the employer can only be informed whether the person can participate in the intended activity[43]. In case of insurance[44], as mentioned previously, presymptomatic or prenatal tests cannot be conducted prior to providing insurance. Art. 27[45] provides on when the insurance providers may not require such tests, and this also includes life insurance which comes up to CHF 400,000, which amounts to more than three crores in rupees. It also allows individuals to take several life and invalidity insurance policies which stay within the stipulated amounts[46]. However, art. 28[47] mentions that insurances not covered by art. 27, may require the applicant to disclose the test results to the designated doctor if- the test provides results that are reliable both technically and in medical practice, and if the results are needed to determine the premiums to be offered. The Human Genetic Testing Act of 2004, provides more on genetic testing in the context of insurance as well. It is also necessary to mentioned that the revised HGTA passed in 2018 and enforced in the year 2022, has an extended scope of application of genetic testing in non-medical purposes[48]. The revised HGTA also reflects clearer rules and requirements

[30] Genetic Information Non-Discrimination Act, 2008, s. 206(a).
[31] Genetic Information Non-Discrimination Act, 2008.
[32] *Id*., s. 207.
[33] Human Genetic Testing Act, 2004.
[34] *Id*., art.1.
[35] *Id*., art. 26.
[36] *Id*., art. 21.
[37] *Id*., art. 3(d).
[38] *Id*., art. 26.
[39] *Id*., art. 3(f).
[40] Human Genetic Testing Act, 2004.
[41] *Ibid.*
[42] *Ibid*.
[43] Human Genetic Testing Act, 2004, art. 24.
[44] *Supra* note 40, art 26.
[45] Human Genetic Testing Act, 2004.
[46] *Ibid.*
[47] *Ibid.*
[48] Andreas Wildi, Lucina Herzog, et.al., "The Revised Law on Human Genetic Testing" *Life Science Recht - Law Journal for Pharma, Biotech, and Medtech* 31-38.

for inter alia, laboratories and provides for advertisement for genetic testing[49]. More importantly, it has strengthened one's personal rights and data privacy in genetic testing[50].

GDPR by the EU, which came into effect in 2018, is a regulation focusing on the protection of the rights of natural persons with respect to their personal data, such as genetic data, its processing and movement[51]. It provides regulations regarding the transfer of personal data to third countries or international organisations[52]. Art. 45[53] specifies that an adequate level of protection is to be ensured in the third country or international organisation in question, and in order to determine such protection, the laws and available redressal remedies relating to the data subjects, the supervisory authorities responsible, and international commitments of the third country or international organisation are to be taken into account. The adequacy of the level of protection is decided by means of implementing act, which will provide for a periodic review at least every four years to take notice of relevant developments in the third country or international organisation[54]. In the absence of such a decision, transfer may be done if enforceable rights and remedies are available for the data subjects and if appropriate safeguards are provided for[55]. The Binding Corporate Rules[56] are to be submitted by companies for approval by the competent data protection authority in the European Union to enable the transfer of data. A list of binding corporate rules approved under the GDPR is also made available[57]. In the absence of the adequacy decision, safeguards, as well as binding corporate rules, the transfers can be done only on the conditions laid down under the GDPR[58].

The H3Africa (Human Hereditary and Health in Africa)[59] has formulated the H3Africa Data Sharing, Access and Release Policy[60] which is built on H3Africa principles of ethics, governance and resource sharing aiming to ensure that adequate safeguards are put in place to protect participants while also encouraging investigators to advance research. The policy lays down procedures regarding data access for users and related conditions to be followed in the process[61]. Access to the data in the European Genome-Phenome Archive (EGA) will be provided to data users approved by the Data and Biospecimen Access Committee (DBAC)[62]. The requests made for data access are reviewed to ensure the absence of inappropriate data use and to ensure compliance with ethical consent[63]. A summary of the proposed research is to be provided by potential data users and the approved users must agree to the Data Access Agreement (DAA) conditions, which aim to protect research participants[64]. The policy differentiates data access for internal and external users[65]. In case where bona-fide scientists working for commercial

[49] *Ibid*.
[50] *Ibid.*
[51] General Data Protection Regulation, 2018, art. 1.
[52] *Id*., art. 44, 45, 46, 47, 48, 49, 50.
[53] General Data Protection Regulation, 2018.
[54] *Id.*, art. 45
[55] *Id.*, art. 46.
[56] *Id.*, art. 47.
[57] Approved Binding Corporate Rules, *available at*: https://www.edpb.europa.eu/our-work-tools/accountability-tools/bcr_en (last visited on May 20, 2024)
[58] *Supra* note 53, art. 49.
[59] H3Africa, *available at*: https://H3Africa.org/ (last visited on May 20, 2024)
[60] H3Africa Consortium Data Sharing, Access and Release Policy, *available at*: https://H3Africa.org/wp-content/uploads/2020/06/H3Africa-Consortium-Data-Access-Release-Policy-April-2020.pdf (last visited on May 20, 2024)
[61] *Id.*, at 7.
[62] *Id.*, at 2,3.
[63] *Id.*, at 7.
[64] *Ibid*.
[65] *Supra*

companies request such access to the data for research or "commercial" purposes, the request is reviewed to ensure that the proposed use of that dataset is scientifically and ethically appropriate and does not conflict with constraints or informed consent limitations[66]. The policy also provides that in case of a breach of the DAA, the agreement will be terminated and the access to such data may be denied in the future as well[67]. This policy[68] of H3Africa focuses on data access and privacy, aiming to protect the privacy and interests of the participants.

Importance of data protection laws to India

India faces serious challenges due to the insufficient laws relating to data protection and is in dire need of an adequate legal framework which would govern sensitive information such as genomic data. The issues discussed concerning India require to be addressed speedily to prevent the continuation of the same due to its sensitive nature. Keeping these issues in mind, an attempt to put forward regulations formulated by countries and organizations abroad has been made with the aim to address the situation. Although the formulations relating to genomic data laid down abroad cannot be applied as is in India, it could still be provided as a guiding tool to formulate a similar framework for the country. They can be considered to be a comprehensive platform from which the most adequate and problem-solving choice may be considered. A few instances of such implementation are put forward although it may not wholly be adequate and satisfactory.

To ensure the proper governance of sequencing of samples done abroad, the procedures followed in the GDPR[69] to ensure that a third country or an international organisation can be transferred personal data, may be used to increase and ensure the security of the data in the third country or international organisation. These regulations may also be framed accordingly to impose conditions over the recipient of the samples exported from India to ensure the protection of such sensitive data. The imposition of such conditions would strengthen the security and manner of handling such data abroad. The GDPR[70] consists of regulations that determine the extent of protection of data that can be ensured and its detailed restrictions enhance the protection of such data while also allowing the transfer and favours attentive governance over the sequencing done abroad.

For the purpose of tightening the security of genomic data accessed by researchers in India as well as by the researchers in companies abroad, the MRCG[71], which has been mentioned earlier as part of the toolkit by GA4GH, allows researchers to search for datasets that have been consented for their research purposes. This is to be done by integrating data sharing terms into consent forms and making it understandable for the machine to read, which then attaches to datasets as per Data Use Ontology terms thereby, allowing consented datasets for specific research purposes to be used by researchers[72]. The terms which can be included for allowing such data access must include conditions such as- reasonable time periods for data access subject to the specific purpose of research, penalties in case of any breach which hinders the protection of such data, and other conditions as considered fit. A slightly similar approach is taken by

[66] *Id.*, at 8.
[67] *Id.*, at 9.
[68] *Supra*
[69] *Supra*
[70] *Ibid.*
[71] *Supra*
[72] *Ibid.*

H3Africa[73] by its reviewing of requests of the researchers, and the DAA, to protect the data from unethical usage.

Though India contains in its Constitution, emphasis on the right to equality, wherein, the prohibition of discrimination on grounds of religion, race, caste, sex, or place of birth[74], equality of opportunity in matters of public employment[75] and right to practice any profession[76] have been made, there is a necessity for an exclusive framework focusing on the prohibition of discrimination with respect to genetic data of an individual in areas of employment and insurance. This not only minimizes such discrimination, but also strengthens the country's legal system. For this purpose, the provisions contained in the GINA, 2008[77] and HGTA, 2004[78], as discussed, may be considered for adoption as per the circumstances of the country. An additional benefit from the consideration of the GINA, 2008 is that it not only deals with such discrimination in employment, but also in employment agencies, labour organisations and in training programs[79]. It also covers the remedies[80] which may be provided to the employees as per the laws they come under. This can be implemented to prohibit discrimination in various levels and sectors of employment in India.

Although the consent of the individual for the use of their biological sample may be taken and is necessary, it still does not protect the data of the individual completely due to its chances of being re-identified. There needs to be a stronger foundation for better and secure actions to be taken in relation to such data. The purpose of highlighting these policies and frameworks is to create a brief platform containing certain laws that can be advisory for creating an adequate framework addressing the challenges of India regarding genomic data. The dire need of a data protection law focusing on such sensitive data is evident to mitigate or, at the very least minimize such issues. The direct acceptance and addition of the stated laws to the Indian legal system cannot be possible and obviously requires alignment with the circumstances of India, for which the lawmakers, through their knowledge and expertise, need to put forward such a law. The frameworks adopted by countries abroad and their objectives are useful in formulating an appropriate law that would address the challenges faced by India therein.

Conclusion

Genomic data, as discussed, is personal data which can reveal one's health conditions, chances of disease, ancestry, characteristics and such. A significant property of genomic data is the presence of commonality among individuals who are blood relatives and hence, its analysis is used for susceptibility risk, paternity and relativeness testing and even for forensic purposes[81]. With the rise in technological advances purporting the use of such data for public health, it is equally necessary to uphold the usage of such data while also halting its misuse by hastily creating a suitable legal framework for its governance and regulation.

[73] *Supra* note 60 at 8.
[74] The Constitution of India, art.15.
[75] *Id*., art.16.
[76] *Id*., art. 19.
[77] *Supra*
[78] *Supra*
[79] *Supra*
[80] *Supra*
[81] Luca Bonomi, Huang Y, *et.al.*, "Privacy Challenges and Research Opportunities for Genomic Data Sharing" 52 *Nature Genetics* (2020).

Each of the laws put forward provide a closely suitable framework to be implemented in India on due consideration. Lawmakers have adequate expertise in taking note of the issues and addressing them suitably. It is necessary to address the challenges such as the manner of sample sequencing conducted abroad, discrimination, and misuse of data, with the creation of a legal framework that aligns with the needs and circumstances of India favouring stringent data protection. The developed framework should encourage responsible data sharing, balancing its benefits with a strong emphasis on the protection of individual privacy and data confidentiality.