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Biodiplomacy: Efforts to Achieve Fairness in Cross-Border Genome Data Transfers

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Abstract

Genome data is currently becoming important data in precision medicine era. The importance of genome data has resulted in increased collection activities worldwide. Until now, there have been no international regulations regarding the activity of sending human genome data across national borders. This has an impact on unequal utilization between countries. Fairness in the use of genome data between countries and the role of Indonesian diplomacy in realizing fairness in the use of genome data are issues in this research. The research method used in this study is a normative legal method that focuses to find and analyze regulations on the regulation of genome data protection in genome data transfer between countries with statute and conceptual approach. The Result shows that in the face of the international regulatory vacuum, countries are divided into three groups, namely countries that prohibit the transfer of genome data, countries that allow it with government permission, and countries that allow the transfer of genome data. To fill the gap in international regulations, Indonesia's diplomatic role is needed to ensure the security of human genome data sent outside its territory.

Keywords

Biodiplomacy; Cross-Border; Data Genome; Fairnes; Transfer.

I. Introduction

Genome Data is data sourced from blood and human body tissue that contains all genetic data of the data subject and their descendants, as well as the susceptibility of the data subject to disease.[1] Genome Data is part of the right to privacy, namely bodily privacy or privacy sourced from the human body. Due to its uniqueness, genome data is currently important data for precision medicine worldwide.[2]

Precision medicine is a new clinical method based on medical data including clinical data, Genome Data, and imaging data to achieve the right diagnosis, treatment, prognosis prediction and disease prevention strategies for each individual.[3] Genome Data is one of the biological factors in helping precision medicine.[4] The use of genome data for

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[1] Georg Hahn et al., "Prediction of Disease-Free Survival for Precision Medicine Using Cooperative Learning on Multi-Omic Data," *Briefings in Bioinformatics* 25, no. 4 (2024): 2, https://doi.org/10.1093/bib/bbae267.

[2] Sinta Dewi, *Cyberlaw: Aspek Data Privasi Menurut Hukum Internasional, Regional, dan Nasional* (Bandung: Refika Aditama, 2022), 41.

[3] Longhui Li et al., "Application of Artificial Intelligence in Precision Medicine for Diabetic Macular Edema," *Asia-Pacific Journal of Ophthalmology* 12, no. 5 (2023): 486, https://doi.org/10.1097/APO.0000000000000583.

[4] Samart Jamrat et al., "A Precision Medicine Approach to Personalized Prescribing Using Genetic and Nongenetic Factors for Clinical Decision-Making," *Computers*

precision medicine has increased the collection of genome data in the world, including Indonesia. Global News Wire noted that the development of medicine using genome data has also contributed 5.6 billion USD in 2022 and is expected to reach 49.3 billion USD in 2023 through genome data utilization medicine.[5]

The increasing economic value of utilizing genome data for precision medicine has an impact on the massive collection of genome data worldwide. It is recorded that genome data collection has been carried out since 1992 until now. Several recent projects in data collection and sharing such as the Human Genome Project,[6] Decode Genetics, Jorean Reference Genome Project, Genome England, and most recently the Qatar National Genome Project.[7] Indonesia is currently also carrying out a genome data collection project through the Biomedical & Genome Science Initiative (BGSi) Project initiated by the Ministry of Health.

For developing countries like Indonesia, the utilization of genome data cannot be done alone considering the limited technology and human resources who are experts in the field of biomolecular and genetic experts for genome data sequencing.[8] This can be seen from the collaboration carried out in the BGSi Indonesia Project with technological cooperation from several platforms such as Illumina, BGI, Oxford Nanopore Technologies,[9] and also MGI Technology based in

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in Biology and Medicine 165 (2023): 1, https://doi.org/10.1016/j.compbiomed.2023.107329.

[5] Joy Y. Zhang, “Commoning Genomic Solidarity to Improve Global Health Equality,” *Cell Genomics* (2024): 1, https://doi.org/10.1016/j.xgen.2023.100405.

[6] Yoshiyuki Sakaki, “A Japanese History of the Human Genome Project,” *Proceedings of the Japan Academy Series B: Physical and Biological Sciences* 95, no. 8 (2019): 446, https://doi.org/10.2183/pjab.95.031.

[7] Fida K. Dankar and Radja Badji, “A Risk-Based Framework for Biomedical Data Sharing,” *Journal of Biomedical Informatics* 66 (2017): 231.

[8] Iqbal Muhammad, “Pengurus Besar Ikatan Dokter Indonesia,” *Liputan6.com*, accessed August 10, 2025, https://www.liputan6.com/health/read/5338904/proyek-genom-bgsi-kemenkes-terus-jalan-idi-nilai-indonesia-masih-minim-ahli-biomolekuler?page=4.

[9] *Ibid*.

China as a provider of 10,000 genome databases.[10] Although currently still in the collection stage, it does not rule out the possibility that in the future further processing will be carried out through international cooperation through sending genome data.

Transfer of genome data outside a country's territory has vulnerabilities, especially in protecting genome data.[11] Guarantees of genome data security and potential losses for the sending country are issues in protecting genome data. Indonesia in the case of Bird Flu in 2005 has experienced a negative impact in the transfer of genome data where Indonesia has shared samples of the flu virus that have been isolated from the Indonesian community to the Global Influenza Surveillance Network (GISN) pioneered by WHO, which ultimately resulted in the results of the samples being used as vaccines and patented by companies in the United States and Europe, namely Hawaii Biotech Inc and Novavax Inc, and Protelix Inc.[12] The same practice is also experienced by China,[13] West African countries,[14] and South African countries.[15]

In addition to the issue of ensuring genome data security, national security issues are also a problem in genome data transfer. Genome data

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[10] "National Genome Project in Indonesia Picks MGI as Technology Provider," *BioSpectrum Asia Edition*, August 25, 2022, accessed August 10, 2025, https://www.biospectrumasia.com/news/93/20932/national-genome-project-in-indonesia-picks-mgi-as-technology-provider.html.

[11] Jin Li et al., "Development of a Risk Index for Cross-Border Data Movement," *Data Science and Management* 5 (2022): 97, https://doi.org/10.1016/j.dsm.2022.05.003.

[12] Devica Rulli Masrur et al., "Biopiracy and the Regulatory Framework for Material Transfer Agreements in Indonesia," *Law Reform: Jurnal Pembaharuan Hukum* 20, no. 1 (2024): 79–80, https://doi.org/10.14710/lr.v20i1.57001.

[13] Yongxi Chen and Lingqiao Song, "China: Concurring Regulation of Cross-Border Genomic Data Sharing for Statist Control and Individual Protection," *Human Genetics* 137, no. 8 (2018): 608, https://doi.org/10.1007/s00439-018-1903-2.

[14] Keymanthri Moodley et al., "Ethics and Governance Challenges Related to Genomic Data Sharing in Southern Africa: The Case of SARS-CoV-2," 2022, 1855, https://doi.org/10.1016/S2214-109X(22)00417-X.

[15] *Ibid.*

editing through biotechnology is also a concern for national security.[16] Moreover, until now, the national legislation of each country still varies due to the absence of regulations in International Law regarding Human Genome Engineering. Based on the Legislation of Twenty-five Countries, it is classified that 4 countries prohibit according to the prohibition instructions, 9 countries regulate but do not explicitly prohibit it and 1 country with restrictions. The United States does not prohibit human genome engineering, and China, India, Ireland and Japan provide conditional or indefinite prohibitions in their national legislation. England in its national legislation also allows for human genome engineering.[17]

Both issues raise concerns about the use of genome data in the future. Whereas genome data is very important for precision medicine for humans, including for the Indonesian people. Differences in views and treatment by countries towards the use of genome data must be addressed with Indonesian diplomatic actions in strengthening Indonesia's position for the use of genome data amidst its shortcomings. Discussions related to the use of genome data through genome data transfer to date can be classified into several schools of thought, namely thoughts that prohibit the transfer and sharing of genome data and thoughts that state that the transfer and sharing of genome data is very important for the advancement of world science and medicine. The discussion can be seen in the table below:

Table 1: Systematic Literature Review on Utilization of Genome Data

Author's Name	Years	Discussion
Senjuti Saha in "Overcoming	2024	The concerns of countries to share genome data due to data colonialism that has occurred for decades. This has an impact

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[16] K. Esvelt and P.D. Millet, "Genome Editing as a National Security Threat," *OIE Revue Scientifique et Technique* 36, no. 2 (2017): 459, https://doi.org/10.20506/rst.36.2.2666.

[17] Shuang Liu, "Legal Reflections on the Case of Genome-Edited Babies," *Global Health Research and Policy* 24, no. 5 (2020): 2, https://doi.org/10.1186/s41256-020-00153-4.

colonialism in pathogen genomics" [18]		on the reluctance of countries to share data
Tuoyu Liu, et all in "Cyberbiosecurity: Advancements in DNA-based information security"[19]	2024	Currently genetic data storage is carried out with artificial intelligence, where the protection space by the state becomes more vulnerable
Major, Rami M in "The public-private research ecosystem in the genome editing era" [20]	2024	Brought the idea of Public-Private Partnership in Genome Data research to reduce research costs
Gesine Richter in "Attitude towards consent-free research use of personal medical data in the general German population" [21]	2024	The collaboration between private companies through their funding has succeeded in conducting research and increasing public trust in the discovery of the Covid-19 vaccine
Joy Y Zhang in "Commoning genomic solidarity to improve global health equality" [22]	2024	Three models in regulating genome data transfer, namely closed, open with consent, and freedom in genome data transfer

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[18] Senjuti Saha et al., "Overcoming Colonialism in Pathogen Genomics," *Lancet Digital Health* 6 (2024): 520–525.

[19] Tuoyu Liu et al., "Cyberbiosecurity: Advancements in DNA-Based Information Security," *Biosafety and Health* (2024): 106, https://doi.org/10.1016/j.bsheal.2024.06.002.

[20] Rami M. Major, "The Public-Private Research Ecosystem in the Genome Editing Era," *iScience* 27, no. 621 (2024): 1–13, https://doi.org/10.1016/j.isci.2024.109896.

[21] Gesine Richter et al., "Attitude towards Consent-Free Research Use of Personal Medical Data in the General German Population," *Heliyon* 10 (2024): 1–9, https://doi.org/10.1016/j.heliyon.2024.e27933.

[22] Joy. Y Zhang, *Op.cit*, 2024, pp 1-7.

Jin Li in "Development of a risk index for cross-border data movement, Data Science and Management" [23]	2022	Transfer of data from one country to another has risks related to data security and data sovereignty
Laith Al-Eitan in "Biosafety and biosecurity in the era of biotechnology: The Middle East region" [24]	2022	There is negative potential in the use of genome data, namely Bioweapons, Economic Losses and Genome Data Editing

All previous discussions are still focused on the approval or prohibition of genome data transfer outside a country's territory. In this article, we will focus on the role of Indonesian diplomacy in genome data transfer for equitable genome data utilization. This issue is important to raise considering that currently state regulations regarding genome data utilization vary greatly and prioritize their interests, so it is necessary to strengthen Indonesian diplomacy in utilizing Indonesian citizens' genome data to avoid irresponsible exploitation by other countries.

II. Method

The research method used in this study is a normative legal method that focuses to find and analyze regulations on the regulation of genome data protection in genome data transfer between countries with statute and conceptual approach. There are two sources and types of data used in this study, namely primary and secondary data sources. The primary

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[23] Jin Li, et all, *Op.cit*, pp. 97-104.

[24] Laith AL-Eitan and Malek Alnemri, "Biosafety and Biosecurity in the Era of Biotechnology: The Middle East Region," *Journal of Biosafety and Biosecurity* 4 (2022): 130–145, https://doi.org/10.1016/j.jobb.2022.11.002.

data sources obtained come from laws and regulations and other relevant legal regulations. While secondary data is obtained from references such as books, journals, literature reviews, documentation, publications, existing research studies, and sources from the internet. About the research subject in detail.

III. Indonesian Practices and Legislation on Genome Data Transfer

Cancer is one of the diseases that can be treated by utilizing genome data. The Minister of Health of the Republic of Indonesia said that Indonesia is currently facing a major challenge in handling cancer. More than 400,000 new cancer cases emerge with 230,000 deaths from cancer each year. [25] The increasing number of patients who die from cancer in Indonesia should be able to be suppressed through early examinations that can be examined through the Genome Data they have or their descendants. This is what Indonesia is currently doing with a genome data collection project to develop a comprehensive genomic profile, as a step towards more precise cancer treatment. The collection of genome data is intended for the utilization of genome data for the Indonesian people.

Genome Data Collection in Indonesia has been carried out massively. At least several genome data collection projects have been recorded in Indonesia. In 2010, FK UI through the Department of Biology conducted a cryosome examination in collaboration with the Department of Medical Genetics, Universitair Medisch Centrum Utrecht, the Netherlands using technology from the Illumina platform.

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[25] Kementerian Kesehatan Republik Indonesia, “Menkes Budi Perkuat Komitmen Indonesia dalam Perangi Kanker,” *Sehat Negeriku*, October 3, 2024, accessed August 10, 2025, https://sehatnegeriku.kemkes.go.id/baca/rilis-media/20241003/4946537/menkes-budi-perkuat-komitmen-indonesia-dalam-perangi-kanker/.

[26] Then in 2016 there was the GenomeAsia 100K Project based in Singapore, where 68 genome samples were samples of Indonesian citizens. [27] The last and still ongoing is the Indonesian National Genome Project (BGSI) which aims to collect genetic data from more than 10,000 Indonesian individuals where this project uses MGI Technology based in China as a provider of 10,000 genome databases, [28] as well as collaboration of several funding platforms from East Venture and Technology from NalaGenetics, a company based in Singapore. [29]
The BGSI project carried out by the Indonesian Government has now succeeded in obtaining 7,074 donors with genome data sequencing carried out on 770 samples conducted by 11 research facilities. For more details, please see the table below:

Table 2. Number of Indonesian Genome Data Sequencing in the BGSI Project as of November 11, 2024.

No	Facility Name	Number of Genome Data Collected
1	Central Hub	0
2	RS Jantung dan Pembuluh Darah Harapan Kita	0
3	RS Kanker Dharmais	404

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[26] Yulia Ariani et al., "Genetics and Genomic Medicine in Indonesia," *Molecular Genetics & Genomic Medicine*, Wiley Periodicals, Inc., 2017, 105, https://doi.org/10.1002/mgg3.284.

[27] *Ibid.*

[28] "National Genome Project in Indonesia Picks MGI as Technology Provider," *BioSpectrum Asia Edition*, August 25, 2022, accessed August 10, 2025, https://www.biospectrumasia.com/news/93/20932/national-genome-project-in-indonesia-picks-mgi-as-technology-provider.html.

[29] Kementerian Kesehatan Republik Indonesia, "East Ventures, Kementerian Kesehatan, dan NalaGenetics Menandatangani Nota Kesepahaman (Memorandum of Understanding) dalam Mendukung Pengembangan Pemeriksaan Genomik," *Sehat Negeriku*, October 19, 2023, accessed August 10, 2025, https://sehatnegeriku.kemkes.go.id/baca/umum/20231018/2944049/east-ventures-kementerian-kesehatan-dan-nalagenetics-menandatangani-nota-kesepahaman-memorandum-of-understanding-dalam-mendukung-pemeriksaan-genomik/.

4	RS Ngoerah	0
5	RS. Persahabatan	0
6	RS. Sardjito	9
7	RSAB Harapan Kita	77
8	RSCM	59
9	RSJPAD Harapan Kita	0
10	RSPI Sulianti Saroso	0
11	RS Pusat Otak Nasional	221
Total		**770**

Source: processed from BGSI.Kemenkes.go.id[30]

From the data above, it can be seen that currently genome data collection is continuing, even BGSI is targeting the collection of 400,000 genome data samples by 2029.[31] The genome data does not rule out the possibility of further processing, either by sending the data outside of Indonesia or by conducting research on the data by foreign parties as is currently being done by many other countries. For example, Mexico, India and Brazil provide government approval requirements for the transfer of genome data outside their country's territory, [32] another example is England which allows the transfer and sharing of genome data outside its country for the development of research and treatment. [33] Sending Genome Data outside a country's territory is necessary to reduce the cost of sequencing/processing Genome Data for use, [34] and

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[30] Kementerian Kesehatan Republik Indonesia, "Dashboard Monitoring & Evaluasi BGSi," diakses 15 Agustus 2025, https://dashboard.kemkes.go.id/views/MonitoringEvaluationBGSi/DashboardMonevBGSiSample?%3Adisplay_count=n&%3Aembed=y&%3AisGuestRedirectFromVizportal=y&%3Aorigin=viz_share_link&%3AshowAppBanner=false&%3AshowVizHome=n.https://dashboard.kemkes.go.id/views/MonitoringEvaluationBGSi/DashboardMonevBGSiSample?%3Adisplay_count=n&%3Aembed=y&%3AisGuestRedirectFromVizportal=y&%3Aorigin=viz_share_link&%3AshowAppBanner=false&%3AshowVizHome=n

[31] *Ibid*.

[32] Joy. Y Zhang, *Op.cit*, pp. 1-2.

[33] *Ibid*.

[34] Olabode Ebenezer Omotoso, "Bridging the Genomic Data Gap in Africa: Implications for Global Disease Burdens," *Globalization and Health* 18, no. 103 (2022): 6, https://doi.org/10.1186/s12992-022-00898-2.

to help develop biomedical research. Especially for countries that do not yet have experts and technology in the field of genome data sequencing, [35] such as Indonesia.

In addition to the benefits received by developing countries such as Indonesia, the transfer and sharing of genome data brings several threats, such as Genetic blackmailing, Genomic discrimination and further risks for relatives of genome data owners. [36] The transfer and sharing of genome data is also very vulnerable to various attacks, especially regarding identity tracking, disclosure of the identity of himself and his descendants and attacks on other individuals. [37] The transfer and sharing of genome data has a high potential for violation of the right to privacy, especially for Genome Data for Genome Data subjects. In addition, the transfer and sharing of genome data also poses the potential for national security disturbances.

In 2016, the Director of U.S. National Intelligence stated that the collection of genome data has received the attention of national intelligence agencies because it is a national security issue. Genome data can be engineered using biotechnology so that it has the potential to become a biological weapon that can be misused by individuals or hostile countries in the future. [38] This statement is certainly a warning for Indonesia in transferring Genome Data outside of Indonesia, because until now there has been no international regulation that provides rules related to the protection of Genome Data in Genome Data transfer activities.

Under international law, there are no regulations regarding the transfer of human genome data. Currently, there are only regulations

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[35] Shuang Wang et al., "Genome Privacy: Challenges, Technical Approaches to Mitigate Risk, and Ethical Considerations in the United States," *Annals of the New York Academy of Sciences* (2016): 8.

[36] Muhalb M. Alsaffar et al., "Digital DNA Lifecycle Security and Privacy: An Overview," *Briefings in Bioinformatics* 23, no. 2 (2022): 2, https://doi.org/10.1093/bib/bbab607.

[37] Rastislav Hekel, "Privacy-Preserving Storage of Sequenced Genomic Data," *BMC Genomics* 22, no. 1 (2021): 2, https://doi.org/10.1186/s12864-021-07996-2.

[38] K. Esvelt and P.D. Millet, "Genome Editing as a National Security Threat," *OIE Revue Scientifique et Technique* 36, no. 2 (2017): 459, https://doi.org/10.20506/rst.36.2.2666.

regarding the transfer of genome data specifically for plants and animals as regulated in the Convention on Biodiversity and the Nagoya Protocol.[39] So there are no regulations that provide responsibility in the form of rights and obligations from countries to protect genome data in genome data transfer activities outside the country's territory.

In responding to the needs and provisions for genome data transfer, Indonesia regulates genome data transfer activities outside Indonesia which can be found in several laws and regulations. Historically, regulations regarding genome data transfer are regulated in Law Number 39 of 2009 concerning Health (has now been revoked and replaced with Law 17 of 2023 concerning Health), the provisions of which stipulate that the sending of specimens or body parts is carried out in the context of organizing health research and development, health services, education and other interests. Other interests are surveillance, investigation of Extraordinary Events (KLB), quality standards for the safety and security of health laboratories as determinants of the diagnosis of infectious diseases, efforts to collect microorganisms, collections of materials, and genetic data from patients and disease-causing agents. These provisions do not explicitly mention genome data as material that can be sent abroad.

This provision was then refined by Law Number 17 of 2023 concerning Health, which stipulates that in order to support Health Services, the Government encourages the use of Health Technology, including biomedical technology that includes genomic technology. Genome Data Transfer can be carried out as long as it obtains approval from the Government in terms of how to achieve the intent and purpose of the examination cannot be carried out in Indonesia, the examination can be carried out in Indonesia but to achieve the main objective of the research, it is necessary to carry out the examination outside the territory of Indonesia and/or for the sake of quality control in order to update the accuracy of diagnostic and therapeutic standard capabilities.

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[39] Dirk W. Lachenmeier and Christophe Montagnon, "Convention on Biological Diversity (CBD) and the Nagoya Protocol: Implications and Compliance Strategies for the Global Coffee Community," *Foods* 13, no. 2 (2024): 2, https://doi.org/10.3390/foods13020254.

Based on these regulations, the practice of genome data transfer can be carried out. This is also the basis for the practice of genome data transfer outside the territory of Indonesia that has been carried out so far. The legal basis is then strengthened by its implementing regulations contained in the Regulation of the Minister of Health Number 85 of 2020 concerning the Transfer and Use of Material, Information Content and Data. Article 4 stipulates that the activity of collecting genetic material and data from patients and disease-causing agents and empowering all resources and public health service facilities by using domestic and foreign assistance and cooperation, for the benefit of health as national resilience. Article 7 of the MTA Minister of Health Regulation stipulates that the legal subjects of the agreement for the transfer of Genome Data material outside the territory of Indonesia are the Sending Institution and the Receiving Institution which include Research Institutions, Educational Institutions and Clinical Laboratories. The custom in agreements made by Research and development companies in collaboration is related to intellectual property rights over discoveries resulting from collaboration in the form of ex ante or ex post agreements to avoid joint intellectual property rights over the discoveries.[40] Research Institutions and Other Institutions are Non-State Actors that are subject to the laws of the country where they are domiciled/have legal status.[41] The State cannot provide legal protection through maximum punishment against entities that are not under its jurisdiction, such as coercive efforts to return and/or destroy genome data that has been obtained by the Institution. The punishments that can be given as regulated in Article 42 paragraph (1) of the MTA Ministerial Regulation are in the form of written warnings, revocation of approval, publication of violations to the public and scientific circles and inclusion on a blacklist.

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[40] David B. Audretsch et al., *Technology Transfer in a Global Economy* (New York: Springer Science+Business Media, 2012), 124.

[41] Midori Ogasawara, "Legalizing Illegal Mass Surveillance: A Transnational Perspective on Canada's Legislative Response to the Expansion of Security Intelligence," *Canadian Journal of Law and Society* 37, no. 2 (2022): 322, https://doi.org/10.1017/cls.2022.9.

The legal subject[42] in the Material Transfer Agreement is subject to the laws of each country where the legal entity status is located. Consequently, if Genome Data is sent to a country that freely allows the transfer of Genome Data outside its territory, it will result in a loss of control[43] and national security. For example, internet service providers such as Microsoft, Yahoo!, Google, Facebook, Pal Talk, YouTube, Skype, AOL, and Apple provide their consumers' personal data to the United States National Security Agency in the PRISM Program. [44] This case shows that foreign institutions also have obligations under their national laws, including to submit their data to their country on the basis of national security. This condition is certainly not beneficial for Indonesia and has the potential to become a threat to Indonesia's national security.

The platforms used by Indonesia in the BGSI Project, namely Illumina based in the United States, Oxford Nanopore based in the United Kingdom and BGI (Beijing Genomics Institute) based in China, also have the potential to have a conflict of interest in the genome data of Indonesian citizens in their country in the genome data sequencing process. The United States with its National Security Act policy can at any time take genome data in the Illumina database. [45] The United Kingdom with its open database policy can ask Oxford Nanopore to

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[42] Kelsen divides legal subjects into two groups, namely natural persons and juristic persons. Individuals. Juristic persons are the equivalent of legal persons which are translated into Indonesian law as Legal Entities, which in order to obtain Legal Entity status must go through an administrative process to the State. For more information, see Nani Mulyati, *Pertanggungjawaban Pidana Korporasi* (Depok: RajaGrafindo, 2022), 24.

[43] Currently, data sharing options cover a spectrum ranging from open access databases without any restrictions as in US GenBank and the European Nucleotide Archive. For more see Keymanthri Moodley et al., *Op.cit.*

[44] In the concept of Science Diplomacy, each country will try to promote its scientific community by facilitating cooperation with other countries through agreements between countries regarding costs, risks and shared benefits obtained from the results of their research, see further Pierre-Bruno Rufini, *Science and Diplomacy: A New Dimension of International Relations* (Gewerbestrasse: Springer International Publishing, 2017), 12.

[45] Simon Chin, "Introducing Independence to the Foreign Intelligence Surveillance Court," *Yale Law Journal* 131, no. 2 (2021): 655.

open the genome data of Indonesian citizens at any time.[46] China with its policy of allowing human genome editing will also have an impact on the risk of genome data of Indonesian citizens.[47]

In this regard, the policy of transferring genome data outside Indonesia should be able to bind the country where the genome data of Indonesian citizens is sent, either through a Bilateral Agreement or by encouraging international regulations for the security of Indonesian citizens' genome data. With the existence of this international agreement, it will certainly have an impact on the security of Indonesian citizens' genome data stored by foreign platforms. For this reason, Indonesian Government diplomacy is needed to maintain Indonesia's position in genome data transfer to protect Indonesian citizens' genome data.

IV. Biodiplomacy: A new direction for safeguarding Indonesian Citizens' Genome Data

Amidst international and national legislative conditions, countries are currently competing to collect genome data. For example, the UK has implemented a genome data collection policy on newborns. This policy was taken to strengthen the UK's position in genome data collection and make the UK the world's genome database.[48] In the next stage, the UK will become a global precision medicine center because it already has a genome database through a free genome data transfer and sharing policy for the advancement of science and medicine. The UK's goal of becoming a precision medicine base will have an impact on increasing

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[46] Joy Y. Zhang, "Commoning Genomic Solidarity to Improve Global Health Equality," *Cell* (2024): 3, https://doi.org/10.1016/j.xgen.2023.100405. See also Joy Y. Zhang, "What Do the British and Chinese Governing Visions on Human Genomic Research Tell Us about Biosovereignty?" *Asian Biotechnology and Development Review* 25, no. 1 (2023): 12.

[47] Yaojin Peng, "Responsible Governance of Human Germline Genome Editing in China," *Biology of Reproduction* 107, no. 1 (2022): 264, https://doi.org/10.1093/biolre/ioac114.

[48] Zhang, *Op.cit.*, 2.

state revenues and the economy of local communities engaged in the health sector, such as hospitals, clinics, hotels, flights, food, tourism, and others.

In addition to England, several countries in the ASEAN region have also developed the potential for precision medicine through stem cell therapy, such as Singapore and Malaysia. They have even been promoting it to Indonesia so that Indonesian citizens can undergo stem cell therapy in that country. This has an impact on the number of Indonesian citizens undergoing stem cell therapy in Singapore and Malaysia. [49] President Joko Widodo said that the large number of Indonesian citizens seeking treatment abroad has resulted in Indonesia losing Rp. 180 trillion every year with Malaysia as the destination country for approximately 1 million patients and Singapore approximately 750 thousand patients. [50] This empirical condition certainly has an impact on the potential economic value of Indonesia and Indonesia's bargaining position in developing sovereignty in the health sector.

Sovereignty means the ability to defend Indonesia's interests, especially in the treatment of Indonesian citizens. This sovereignty can be realized through the independence of the Indonesian nation to process health data including genome data in protecting national interests, both from an economic aspect and the protection of Indonesian citizens themselves. Some weaknesses that can be inventoried in genome data sequencing in developing countries such as Indonesia are the high cost of building genome data sequencing facilities, human resources who are experts in biotechnology and

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[49] One of Malaysia's health clinics, Regena Medical, said that every week around 50-60 Indonesian citizens undergo stem cell therapy at its clinic. See more Antara, "Regena Medical Centre Gandeng Permai Penang dalam Bidang Kesehatan," April 17, 2021, accessed August 15, 2025, https://www.antaranews.com/berita/2106986/regena-medical-centre-gandeng-permai-penang-dalam-bidang-kesehatan.

[50] Puja Pratama, "Infografik: Hundreds of Trillions Lost Due to Medical Treatment Abroad," *Katadata.co.id*, accessed August 15, 2025, https://katadata.co.id/infografik/663053b419b50/infografik-ratusan-triliunan-melayang-karena-berobat-ke-luar-negeri.

molecular, lack of tools in genome data analysis and weak regulatory frameworks. [51]

In order to create sovereignty in the health sector, especially genome data sovereignty, the role of Indonesian diplomacy is needed, or what is known as biodiplomacy. The term biodiplomacy has appeared in the literature with various meanings. The following is a brief description of the various meanings of biodiplomacy to clarify the context of its use in various publications compared to its use here. One of the first publications appeared in 1994 and focused on negotiations on the conservation and sustainable use of the world's biological resources, especially from developing countries. [52] In the concept of science diplomacy, each country will strive to promote its scientific community by facilitating cooperation with other countries through agreements between countries for agreements on costs, risks and shared benefits obtained from the results of their research. [53]Biodiplomacy is built on a more critical understanding of diplomatic practice, which does not exclusively see it as an elitist, secular, or static practice, but also as a practice related to efforts to contain conflict, create the world, and change relationships broadly. [54] Biodiplomacy in this paper has the meaning of an effort by a country, especially a developing country, to maintain biological resources, in this case the human genome data of its country as a support for increasing the value of benefits and protection of its citizens.

In the context of implementing biodiplomacy, Indonesia must at least implement 2 (two) important agendas, namely: internal strengthening and international consolidation.

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[51] Mohamed Helmy, "Limited Resources of Genome Sequencing in Developing Countries: Challenges and Solutions," *Applied & Translational Genomics* 9 (2016): 16, https://doi.org/10.1016/j.atg.2016.03.003.

[52] Alfredo Aguilar and Christian Patermann, "Biodiplomacy, the New Frontier for Bioeconomy," *New Biotechnology* 59 (2020): 24, https://doi.org/10.1016/j.nbt.2020.07.001.

[53] Pierre-Bruno Rufini, *Science and Diplomacy: A New Dimension of International Relations* (Gewerbestrasse: Springer International Publishing, 2017), 12.

[54] Costas M. Constantinou, "On Biodiplomacy: Negotiating Life and Plural Modes of Existence," *Journal of International Political Theory* 17, no. 3 (2021): 3, https://doi.org/10.1177/1755088219877423.

A. Internal Strengthening

In strengthening Indonesia's position in the field of genome data utilization, internal strengthening is first needed. Internal strengthening is Indonesia's effort to improve Indonesia's shortcomings in genome data utilization so far. Some potential internal strengthening are as follows:

a **Improving Indonesia's capabilities in genome data sequencing**

Until now, Indonesia still relies on foreign platforms in genome data sequencing. For example, in the BGSI project which relies on the Illumina, Oxford Nanopore and BGI (Beijing Genomics Institute) platforms, this dependence certainly has a negative impact on Indonesia's sovereignty in protecting its citizens' genome data. For this reason, strengthening is needed through increasing human resources, especially in the fields of biotechnology and biomolecular. Currently, experts in the fields of biotechnology and biomolecular in Indonesia are still minimal, so the Government needs to invest in developing human resources in both fields.

In addition, the limitations of genome data sequencing technology in Indonesia also need to be strengthened. Currently, there are 11 facilities used by the Indonesian government to collect genome data. However, the sequencing still uses resources outside Indonesia. Therefore, investment is needed in Indonesian genome data sequencing technology. BioBank: Expanding the collection of genome data for Indonesian citizens.

b **Improvement of national regulations**

Currently, through the Health Law and its implementing regulations, Indonesia has regulations regarding the utilization and transfer of genome data outside Indonesia. However, these regulations still have weaknesses in their implementation, namely regarding the subject of the genome data transfer agreement where the subject is a non-state actor. In an effort to strengthen Indonesian diplomacy in the utilization and transfer of genome data, it is necessary to reformulate the subject of the agreement into an agreement between countries. This is necessary in order to provide rights and obligations for the country where the genome data is sent in order to provide protection for the genome data of Indonesian citizens. In addition, special regulations are also needed regarding the Utilization and Protection of Genome Data as carried out by several countries. Several countries that provide special regulations related to genome data security are as follows:

Table 3. Special regulations for genome data in several countries.

No	Country	Genome Regulation
1	China	Through the Administrative Regulation of Human Genetic Resources No. 717 of 2019, states that the collection of genomic data is a national security issue.[55]
2	Mexico	the Genomic Sovereignty Act, This regulation regulates: (1) the human genome is both individual and human heritage; (2) personal discrimination based on genetic information is not permitted; (3) participants have the right to safeguard their right to be informed of the results and consequences of a genetic study; (4) genetic infor- mation must be preserved in a confidential manner; (5) human genome research and developments must be regulated to as- sure that the medical and economic benefits derived from this knowledge warrant health protection and respect the human rights, the freedom and the dignity of the individual; and (6) research on human genomics remain under

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[55] China, *Administrative Regulation of Human Genetic Resources*, Article 8, Number 717, 2019.

		a federal regulatory framework to protect the genomic patrimony.[56]
3	Japan	With the Genome Medicine Promotion Act with basic priciple, such are public benefit, bioethical integrity, and protection of information and prevention of discrimination principle.[57]
4	Canada	Through The Genetic Non-Discrimination Act, Bill S201, 2017, which provides full protection for Data Subjects in genetic data collection activities, there is even a criminal threat clause for Providers who force Data Subjects to participate in genetic data collection and leak/disclose the results of genetic data testing..[58]
5	Taiwan	has 2 regulations regarding genome data, namely the Genetic Health Act which was amended on 8 July 2009[59] and the Human Biobank Management Act amended January 20, 2021[60]

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[56] Augusto Rojas-Martínez, "Confidentiality and Data Sharing: Vulnerabilities of the Mexican Genomics Sovereignty Act," *Journal of Community Genetics* 6, no. 3 (2015): 315, https://doi.org/10.1007/s12687-015-0233-5.

[57] *Science Japan*, "A New Law for Promoting Genome Medicine Enacted: Definite Provisions for Preventing Genetic Discrimination and Mandating the Government to Formulate a National Plan," August 25, 2023, accessed August 15, 2025, https://sj.jst.go.jp/stories/2023/s0825-01p.html.

[58] Yvonne Bombard and Bev Heim-Myers, "The Genetic Non-Discrimination Act: Critical for Promoting Health and Science in Canada," *Canadian Medical Association Journal* 190, no. 19 (2018): E579, https://doi.org/10.1503/cmaj.180298..

[59] Taiwan Ministry of Health and Welfare, *Reproductive Health Law*, accessed August 10, 2025, https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0070001.

[60] Taiwan Ministry of Health and Welfare, *Human Biobank Management Act*, accessed August 10, 2025, https://law.moj.gov.tw/Eng/LawClass/LawAll.aspx?PCode=L0020164.

6	Australia	There are 2 (two) regulations regarding genome data, namely Gene Technology Act 2000[61] dan Biosecurity Act 2015[62].

Source: compiled from various sources

B. International consolidation

In addition to internal strengthening, Indonesia also needs to conduct international consolidation to maintain Indonesia's national interests. With the variation of national regulations related to the treatment of genome data throughout the world, the absence of international regulations regarding genome data security will have an impact on the security of Indonesian citizens' genome data in terms of sending genome data outside Indonesia. This international consolidation can be achieved through:

a **Encourage the formation of an international legal framework for protecting genome data**

The lack of international law that binds countries to protect genome data internationally has an impact on the potential for unbalanced use of genome data between countries. This is due to the absence of the principle of transparency and integrity of genome data protection from the results of genome data transfer. So that several cases show that developing countries are always victims of unbalanced genome data collection. An international legal framework is needed to create justice between countries in genome data transfer activities. Indonesia's step by attending and agreeing to the WHO meeting at the Bellagio Center on April 25-28, 2022, regarding the formulation of the WHO Guiding Principles for Pathogen Genome Data Sharing is a good step in fighting for an international legal framework related to global genome data

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[61] Department of Health, Disability and Ageing of Australia, *Gene Technology Act 2000*, accessed August 10, 2025, https://www.legislation.gov.au/C2004A00762/latest/text.

[62] Department of Health, Disability and Ageing of Australia, *Biosecurity Act 2015*, accessed August 10, 2025, https://www.legislation.gov.au/C2015A00061/2020-03-25/downloads.

protection, especially in dealing with a global pandemic such as Covid-19 that hit the world several years ago. The principles of trust and transparency contained in the WHO Guideline are evidence of building a fair international legal framework regarding genome data transfer. However, the softlaw nature of the WHO Guideline needs to be strengthened in the future with Indonesian diplomacy to maintain the interests of protecting Indonesia's genome data. In addition, in substance, the regulation in the WHO Guideline still regulates the responsibility of the platform which must comply with national and international laws. This regulation should be strengthened regarding how the national law of the platform country respects and protects foreign genome data in the platform database in its country.

b **Prepare a framework for bilateral agreements with other countries**

The current condition with the absence of an international legal framework related to the protection of human genome data, especially in the activity of transferring genome data outside the country's territory, must be addressed by Indonesia by making bilateral agreements with various countries. These countries are countries where Indonesia collaborates with platforms such as the United States with the Illumina platform, the United Kingdom with the Oxford Nanopore platform and China with the BGI (Beijing Genomics Institute) platform, all three of which are currently being used by Indonesia in the BGSI Project.

V. Conclusion

Indonesia's collaboration with various genome data sequencing platforms has an impact on the potential security of Indonesian citizens' genome data. The absence of an international legal framework related to genome data protection in genome data transfer activities makes Indonesia's position vulnerable in protecting Indonesian citizens' genome data. In addition, it is necessary to improve national regulations by including international agreements as a condition for sending genome data outside of Indonesia. Through biodiplomacy in the form of internal strengthening, namely increasing Indonesia's ability in genome data sequencing and improving national regulations and international consolidation in the form of efforts to encourage the formation of an international legal framework in protecting genome data and preparing a framework for bilateral agreements with other countries, it is hoped that this can improve Indonesia's position in protecting Indonesian citizens' genome data.

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Accipere quam facere
praestat injuriam