

RESEARCH ARTICLES

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Legal Regime for the Protection of Genetic Information of Indigenous Peoples and Local Communities in International Law

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Abstract: The present study aims at providing an idea that the protection of genetic and genomic information of indigenous peoples and local communities should be legally established at universal and regional levels. There is a trend in many countries towards the disappearance of rare nations and peoples representing genetic diversity. In the case of the collection, processing, storage, transmission of data in the application of artificial intelligence take further action to ensure cybersecurity, develop ethical guidelines and confidentiality requirements for collection and processing genomic and genetic information on the health of indigenous peoples and local communities bearing in mind the provisions of the United Nations Declaration on the Rights of Indigenous Peoples (2007) and the International Convention on the Elimination of All Forms of Racial Discrimination (1965). Although human genes are not covered by the Convention on Biodiversity (1992), it should be applied by analogy in the case of the protection of the “genetic” heritage of mankind. The research uses general scientific and special cognitive techniques wherein legal analysis and synthesis, systemic, formal-legal, comparative-legal, historical-legal and dialectical methods are applied. The author calls on the international community to recognize indigenous genetic information from medical research as the common heritage of mankind and to establish special legal responsibility of present generations for the future of mankind at the universal level. The author of the article notes the importance of prevention the development of racial and ethnic weapons against a certain population group and to prevent the commission of the crime of “genomocide” against indigenous peoples and local communities

and to comply with biosafety measures in conducting scientific research and obtaining certain genetic information, to preserve the uniqueness of the biocode of the nations and peoples inhabiting our planet.

Keywords: biosecurity; cybersecurity; indigenous peoples; genetic information; genomic sovereignty; biocolonial approach; genetic heritage of mankind; UN Sustainable Development Goals

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I. Introduction

Over the past 30 years, human genetics has made impressive progress in reconstructing the history of a population¹ and determining what genes make a person predisposed to a particular disease.² Interest in

¹ As well as answering questions about heritage, population history research can be useful for health research. In 2009, genetic epidemiologist Marlo Moeller and her colleagues at Stellenbosch University in South Africa teamed up with Brenna Henn, a population geneticist at Stanford University, to study the genomes of South African people with a Khesan ancestry. They hoped to find out why people with this background are more susceptible to TB than other groups.

² For example, scientists from the Medical Genetics Research Centre found out that in both ethnic groups, hypotrichosis, a congenital disease in which a person has much less hair than expected, is common in the Chuvash and Mari ethnic groups. This disease is caused by a mutation in a small area of the LIPH gene located on the third chromosome. In addition, another hereditary disease, lethal infantile osteopetrosis, is common in both peoples. Available at: <https://ria.ru/20190417/1552774350.html?in=t> [Accessed 24.01.2022].

genetics has grown rapidly in recent years from population geneticists,³ molecular anthropologists, genetic epidemiologists and paleontological researchers.⁴ A few prominent examples can be mentioned to illustrate this point. For example, in 2017, the first ancient DNA laboratory was established in India with the objective to find out how different populations relate to each other genetically. DNA samples from members of the Havasupai tribe (Havasu ‘Baaja, “people of turquoise water”) in Arizona were gathered to investigate diabetes. A US researcher, Dr Katrina Klaw of the University of Washington, D.C. was wondering why American Indians and Alaska Natives (Iñupiat) absorbed nicotine faster than people of other ethnic backgrounds. The study compared the DNA of Inupiat ancestors in Alaska with DNA of modern people to study the genetic history of the population. Geneticist Tsosie on Diné and Navajo Nations from Vanderbilt University in Nashville (Tennessee, USA), working with a group of Turtle Mountain Chippewa Indians (Turtle Mountain) in North Dakota, researching genetic factors that might explain why in the community some women are more susceptible to preeclampsia during pregnancy⁵ than others. In British Columbia,

³ A striking example is a study by the International Paleogenetics Group, which studied 48 samples of remains of people who lived from three to six thousand years ago in the North Caucasus and compared them with the DNA of other peoples, establishing their kinship with American Indians, indigenous peoples of Siberia and the inhabitants of southern Europe. Thus, genome analysis of the famous Maikop culture, which occupied the territory from the Taman Peninsula to Chechnya, revealed a kinship with the Indians and contemporary Siberian ethnic groups. The Yamnaya culture, which lived in the eastern Caucasian foothills, was genetically linked to the ancient peoples of South and Southeast Europe and their contemporary descendants. Available at: <https://www.nature.com/articles/s41467-018-08220-8> [Accessed 24.01.2022].

⁴ According to a report by scientists from the Institute of Cytology and Genetics of the Siberian Branch of the Russian Academy of Sciences and the University of Pennsylvania (USA), North American Indians and Southern Altai peoples are related. Their common ancestor lived in the Altai 15–20,000 years ago. Experts have compared more than a hundred genetic markers inhabitants of the Northern and Southern Altai, Mongolia and southern Siberia, and also the Indians of North America. As the experts note, “the Altai and Indians are closest to each other in terms of the frequency of the relevant mutations in the genome. Available at [https://www.cell.com/ajhg/fulltext/S0002-9297\(11\)00549-0](https://www.cell.com/ajhg/fulltext/S0002-9297(11)00549-0) [Accessed 24.01.2022].

⁵ A complication of pregnancy that develops after 20 weeks’ gestation characterized by high blood pressure and increases the risk of cramps and preterm birth.

collaborative research effort on excess cardiac mortality in Gitksan First Nation have led to the discovery of a gene combination that contributes to an increased propensity for arrhythmia, and sudden death being an extended interval syndrome of QT. In New Zealand, gout research was conducted in consultation and collaboration with the Maori tribe, Ngāti Porou through its health care provider the Ngāti Porou Hauora Charitable Foundation. That resulted in the identification of genetic variations associated with high levels of uranum in serum in the case of gout and evidence that gout is hereditary. This knowledge has not only improved diagnosis and treatment, but, more importantly to the tribesmen, have de-stigmatized gout as a disease arising from hereditary genetic factors, not as a result of a bad lifestyle.

Such active tribal research is conducted with members of indigenous peoples of African and Latin American origin, local communities in Mexico, New Zealand and Canada, there studies of the Inupiat people of the Arctic Slope in Alaska, the Navajo nation in the United States, and local communities in Hawaii, San communities in Southern Africa, and research on the formation history of some South Asian populations (Phillips, 2019). State recognition of the existence of certain peoples through DNA tests becoming increasingly relevant in state practice (Arnaiz-Villena *et al.*, 2017; Blakemore, 2019), there are precedents for the acquisition of nationality through DNA testing of biomaterials to establish a biological/legal bond (“right to citizenship”).⁶ However, experts point to the abuse of DNA samples without indigenous people consent. In one notorious story, researchers from the University of Arizona took DNA samples from members of the Hawasupai tribe in Arizona in the 1990s for diabetes research, but later used samples without tribal consent to investigate schizophrenia and patterns of mixing and migration. In 2010, the Hawasupai people won a \$ 700,000

⁶ A group of Telugu-speaking people who live in a small village near Guntur in Andhra Pradesh (about 50 families in the village) practice Judaism, and most of them can read and write Hebrew. The researchers believe the community members come from the tribe of Ephraim, one of the ten lost tribes of Israel, and hope that DNA analysis of the members will help them be recognised as Jews. According to researcher Jacoby, some 200 people who gave blood samples now want to know their origins.

lawsuit (Harmon, 2010) and the university was forced to return all DNA samples collected. Indigenous genomes are interesting in their unique variability. New genotype and phenotype relationships found in small isolated groups used to develop personalized medicine. According to researchers, the problem should be approached considering the fact that the project “Diversity of the Human Genome” makes it clear to participants in various sectors of the market that the benefits of the Big Data Economy and genome information is available due to the indigenous peoples of Central and South America (Fox, 2020). There is a huge disproportion in the health of indigenous peoples due to persistent bias including in research work. And personalized medicine is not going to help. Researchers simply cannot publish the study because the results could be detrimental to the indigenous community. That is probably why most genome research is focused on people of European origin. A recently published analysis showed that as of 2018, only 22 % of persons involved in general genomic association research⁷ are of Non-European origin. People of African and Latin American descent and indigenous peoples together accounted for less than 4 % of participants, indicating a lack of diversity of sufficient genetic worldwide research. For example, according to the United Nations,⁸ 370 million people in over 90 countries consider themselves as indigenous peoples representing humanity in all its diversity but what unites them all is that they are the most isolated, discriminated against, endangered and often the poorest communities around the world. Although indigenous peoples make up 5 % of the world’s population, 15 % live in extreme poverty.

⁷ Indigenous and non-indigenous scientists are trying to stop the cycle of separation. In 2011, Ripan Malhi, a molecular anthropologist at the University of Illinois at Urbana-Champaign, started a Summer Internship for Indigenous Peoples in Genomics (SING). The annual week-long course is taught primarily by Indigenous educators and allows people from Indigenous communities, including college and tribal university students, to learn about genomics and discuss its uses and abuses. The workshop was originally funded by the US National Science Foundation and the University of Illinois; it is now supported by the NIH.

⁸ The Indigenous Peoples’ Major Group for Sustainable Development (IPMG) website. Available at: <https://indigenouspeoples-sdg.org/index.php/english/> [Accessed 24.01.2022].

II. General Provisions

The terms “indigenous peoples” (*in Spanish* pueblos indígenas, marginalized populations) and “local congregations/communities/population” (*in Spanish* comunidades campesinas) need more careful study by specialists in international law, as in the legal literature the terms “ethnic minorities” (ethnic minorities; minority ethnic groups, indigenous and other marginalised populations, indigenous tribes, *in Spanish* minorías) and “First Aborigines” (Native Nations, First Nations), which creates further confusion in the legal understanding (Saul, 2002; Abashidze and Sheremet, 2021). International indigenous justice (Wardana, 2012)⁹ is currently emerging. The term “bio-colonial” (Worlds, 2019) is also used by foreign colleagues to inventory the collection of genetic information from indigenous DNA samples. Data sovereignty of indigenous peoples, the concept of “genomic divide,” the concept of genetic division and genetic map, indigenous genetic self-determination and the concept of digital colonization in relation

⁹ See: Jurisprudence of the European Court of Human Rights Regarding Indigenous Peoples: O.B. and Others Against Norway, O.B. & Others, App. No 15997/90, Eur. Comm’n H.R. Dec. & Rep., at 8–9. *Könkäma and 38 other Saami Villages v. Sweden*, App. No 27033/95, Eur. Comm’n H.R. Dec. & Rep. (1996), *Halvar From Against Sweden*, *Johtti Salmelacat RY and Others Against Finland*, *The Muonio Saami Village Against Sweden*; *Hingitag 53 Against Denmark*, *Handolsdalen Sami Village and Others Against Sweden*, *Chagos Islanders Against United Kingdom*. Jurisprudence of the Inter-American Court of Human Rights Regarding Indigenous Peoples: *Kichwa Indigenous People of Sarayaku v. Ecuador*, Merits & Reparations, Judgment, Inter-Am. Ct. H.R. (ser. C) No 245 (June 27, 2012); *Indigenous Communities of the Xingu River Basin in Para v. Brazil*, Inter-Am. Comm’n H.R., Apr. 11, 2011, (PM 382/10); *Salvador Chiriboga v. Ecuador*, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 222 (Mar. 3, 2011); *Xákmok Kásek Indigenous Community v. Paraguay*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 214 (Aug. 24, 2010); *Saramaka People v. Suriname*, Preliminary Objections, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 172 (Nov. 28, 2007); *Sawhoyamaya Indigenous Community v. Paraguay*, Merits, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 146 (Mar. 29, 2006); *Yakye Axa Indigenous Community v. Paraguay*, Inter-Am. Ct. H.R. (ser. C) No 125 (June 17, 2005); *Moiwana Community v. Suriname*, Preliminary Objections, Merits, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 124 (June 15, 2005); *Mayagna (Sumo) Awas Tingni Community v. Nicaragua*, Inter-Am. Ct. H.R. (ser. C) No 79 (Aug. 31, 2001); IACHR, Report No 96/03, Case 12.053, *Maya Indigenous Communities of the Toledo District (Belize)*, October 24, 2003.

to indigenous peoples, and the right to return¹⁰ to one's home country are a vivid proof.

For example, the Maori have adopted the Treaty of Waitangi¹¹ which enshrines traditional values and rights of indigenous peoples to the protection of data important to them in modern digital systems; the document establishes the obligation to consult with Maori and indigenous peoples at all levels of policy, legislation and development of any systems that contain Maori data, including the use of artificial intelligence to avoid inadvertent bias and negative consequences.

In particular, indigenous peoples and local communities are a vulnerable category in international human rights law and it is vital to uphold the requirements of confidentiality, voluntariness and legal and obtaining the legal written consent¹² of participants in genetic research, protecting the personal data of those involved, their rights to participation and representation in research bodies, and the collective rights of indigenous peoples to genetic resources as set forth in international instruments.

The goals enshrined in the 2030 Agenda for Sustainable Development (resolution 70/1, adopted by the UN General Assembly in 2015)¹³ provide an unprecedented opportunity to guarantee indigenous peoples participation. Indigenous knowledge on topics such as community resilience and the environment, for example, can be used in achieving the goals (Anisimov and Gulyaeva, 2021). For example, for the first time, the law of the sea¹⁴ will provide legal protection for indigenous and local

¹⁰ Application No 35622/04, *Chagos Islanders v. the United Kingdom*, ECHR Decision of 2012.

¹¹ The Treaty of Waitangi. Available at: <https://www.taiuru.maori.nz/maori-data-sovereignty-and-digital-colonisation/> [Accessed 24.01.2022].

¹² In 2016, Suzman, who worked with San communities in southern Africa for nearly 30 years, led a workshop to develop a standard process for obtaining consent to research for two specific groups. After a two-day discussion of genomic research, community leaders told Suzman that they did not understand genetics and would prefer to have a trusted person to negotiate for them to participate in the study.

¹³ Transforming our world: the 2030 Agenda for Sustainable Development UN General Assembly. 2015. 21 October. UN Doc. A/RES/70/1.

¹⁴ Specialised international access and benefit-sharing instruments in the context of Article 4, paragraph 4 of the Nagoya Protocol CBD/SBI/3/14 of 13 July 2020, pp. 12–13; UNEP. UNEP/CBD-SBSTTA/11/11, Par. 44 of 22 July 2005. Available

communities (Anisimov and Gulyaeva, 2021) traditional knowledge of marine genetic resources at the universal level, as well as a specific mechanism to control stakeholders' access to this knowledge. The fact that indigenous traditional knowledge falls within the definitions of intangible cultural heritage raises the question of the overlap between the scope of the future Agreement and the 2003 Convention for the Safeguarding of the Intangible Cultural Heritage.¹⁵

Moreover, genetic information and data, as well as relevant marine and biotechnological information are the subject of intellectual rights, which falls within the purview of WIPO. Accordingly, it is strange to see a simplification of the definition of MGM in the Revised Draft, which is formulated along the lines of the definition of genetic material in the Convention on Biological Diversity and does not contain any reference to maritime zones or corresponding exemptions. As the omics sciences and genomics in particular, evolve, large volumes of complexly organized data (*Big Data*) are accumulating, leading to a close interaction of advocacy mechanisms with bioinformatics and biostatistics.¹⁶ The Genome Aggregation Database (GnomAD),¹⁷ used mainly as a reference tool to interpret sequencing data and understand variants associated with disease on a global scale, is not subject to generalization. The GnomAD genetic database does not include the

at: <https://www.cbd.int/doc/meetings/sbstta/sbstta-11/official/sbstta-11-11-en.pdf> [Accessed 09.08.2021]; United Nations. Sustainable Development GOALS. Goal 14: Conserve and sustainably use the oceans, seas and marine resources. Available at: <https://www.un.org/sustainabledevelopment/oceans/> [Accessed 24.01.2022].

¹⁵ Convention for the Safeguarding of the Intangible Cultural Heritage adopted on 17 October 2003 by the General Conference of the United Nations Educational, Scientific and Cultural Organization. Available at: https://www.un.org/ru/documents/decl_conv/conventions/cultural_heritage_conv.shtml [Accessed 24.01.2022].

¹⁶ The European Bioinformatics Community for Mass Spectrometry. Available at: <https://eubic-ms.org/> [Accessed 24.01.2022].

¹⁷ The Genome Aggregation Database (GnomAD) is a resource developed by an international coalition of researchers to aggregate and harmonize exome and genome sequencing data from a wide range of large-scale sequencing projects and provide aggregated data for the wider scientific community. Available at: <https://gnomad.broadinstitute.org/> [Accessed 21.01.2022]. The v2.1.1 (GRCh37/hg19) dataset available on the official website includes 125,748 exome sequences and 15,708 whole-genome sequences of unrelated individuals (humans) sequenced in various disease-specific genetic and population genetic studies.

indigenous population of the planet, and therefore, the results may be misleading or even detrimental to the rights of these groups. Without taking into account the biological data of the indigenous peoples of the world, the success of genomic medicine can be called into question. For this reason, worldwide efforts are under way to establish a BVDs genetic database¹⁸ for previously excluded populations, recognizing that both affiliated policies and science infrastructure are needed. Without that, the success and benefits of genomic medicine are disproportional. It should be highlighted that in North America, China and Europe, a scientific project involving geneticists called the *Human Genome Diversity Project* (“Diversity Project”/“Project”/“HGDP”) has been initiated to try to create a collection of indigenous genetic material from all over the world (Greely, 1997; Cavalli-Sforza and Cavalli-Sforza, 1995, pp. 258–259; Cavalli-Sforza *et al.*, 1997).

With the development of genomic technology and genetic engineering, nations are seeking new ways and methods to ensure the biosafety of both the individual and society as a whole. There is a growing global awareness of the need for effective protection of constitutional and civil human rights through scientific research and its subsequent applications.

Alongside the purely legal issues, genomic research raises a number of general *socio-ethical and moral conflicts*. After all, the undeniable benefits of the research in question are often fraught with potential risks to human and public health, the environment and the ecology. The bioethical aspects and moral dilemmas of genetic screening have now come to the fore: protection of confidentiality of data or disclosure for biosafety; personal choice or coercion of members of the public; voluntary or mandatory screening; and discrimination and stigmatization on genetic grounds such as Cold Winters Theory. There is a need to develop effective ethical and legal ways of dealing with the challenges posed by the introduction of genetic-based personalized medicine technologies into the clinic. Here it is important to respect the bioethical principle of justice, combined with the classical principle of

¹⁸ Background variant databases (BVDs) for genetic diagnosis across the globe. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7193324/> [Accessed 24.01.2022].

“do no harm” by unnecessary knowledge about one’s genome (Furrow *et al.*, 2013).

In doing so, information derived from genetic data should not be used to harm or discriminate against individuals, families or groups in both clinical and non-clinical spheres, including employment, insurance, access to social inclusion and opportunities to increase general well-being (European Commission, 2004, p. 26).

One example of genome research is a study of the Nuu Cha Nult people in British Columbia, Canada, whose blood samples were originally collected in order to understand the cause of the high morbidity and severity of rheumatoid arthritis. Instead, DNA was used to study human migration and retroviruses. Another equally striking example is the controversial study of the “warrior” gene conducted on Maori in New Zealand, which, based on a relatively small sample, were said to be more likely that the assumed higher frequency of the monoamine oxidase gene variant, as was previously the case, related to the aggressive behavior of the non-indigenous population which explains the aggressive behavior of some Maori.

This research has been widely condemned for reinforcing unjustifiably negative stereotypes of Maori as inherently violent. Attention should be drawn to the observance in indigenous genetic research of the 1965 Convention on the Elimination of All Forms of Racial Discrimination, which enshrines the basic principle of international law that all human beings are equal, that all States shall work to eradicate racial discrimination, that is to say, any distinction, exclusion, restriction or preference based on race, color, descent, or national or ethnic origin having as its purpose or effect the destruction or impairment of the rights of persons belonging to indigenous peoples, and that it shall be applied in the case of indigenous peoples.

Biological and medical research, biotechnological developments have led to impressive achievements in the field of health care. However, these achievements raise ethical issues that affect the protection of human rights and dignity in the field of genetics, transplantation of organs, tissues, cells and embryos, the creation of national and personalized biobanks,¹⁹ use of modern technologies in the creation

¹⁹ A biobank is a type of biorepository, a specialized repository of biological materials for scientific and medical purposes, accompanied by information about them (Smirnova, 2013).

of databases on health, *etc.* In this context, not only positive legal regulation is developing but also topical public discussions about the so-called “genetic responsibility.”

The moral concept of “genetic responsibility” (GR) is relatively young in EU law and has been associated with a progressively increasing sense of responsibility (“responsibilisation”) in the health care field (Leefmann, Schaper, and Schicktanz, 2017). It emerged within the framework of discussions on genetic testing in the 1970s, to promote reproductive positive eugenics and to imply a collective responsibility towards future generations to avoid inheriting diseases (Lipkin and Rowley, 1974, pp. 93–100), a term coined by scientists Lipkin and Rowley.

In addition, the phenomenon of “responsibility” has many conceptual and historical meanings in bioethics (Schicktanz and Schweda, 2012, pp. 131–145). In the 2000s, this concept of “genetic responsibility” was closely linked to the development of the concept of the influence of biopolitics and the genetic approach on the individual’s perception of himself (“genetic thought style”) and thus on the socio-political sphere of his action (Lemke, 2006, pp. 83–91; Denisenko and Trikoz, 2020).

International instruments and existing European regulations recognize everyone has the right to know his or her own medical and genetic information and the right not to know. However, the professional community of doctors, employers and common laymen do not always agree on this problem of “genetic responsibility.” Most are leaning towards the “calm” version of ignorance as opposed to the “responsible” knowledge.

Not long ago, a comparative study was conducted among German and Israeli residents on their moral attitudes towards “*genetic responsibility*.” Three main aspects of this responsibility were examined: personal responsibility, responsibility for loved ones, and the responsibility of society towards its members. Ethnocultural differences in the responses of German and Israeli respondents showed serious differences, and a moral conflict was identified between the right to confidentiality and the moral obligation to disclose genetic information to relatives (responsibility for relatives). There was also a disagreement on the more personal issue of the right not to know genetic information

about oneself combined with the duty to know and make a responsible decision (personal responsibility). In summary, the study showed that the moral assessments of the Israelis were more oriented towards the public interest, while the Germans expressed an attitude towards the rights and interests of the individual in their assessments (Raz and Schichtanz, 2009).

The collection, processing, use, research, storage and transmission of genetic information about the world's indigenous peoples and local communities, and the subsequent application of the data acquired, constitute an invaluable contribution to knowledge of the history of human evolution and human capital. Nevertheless, it must be understood that the collection, processing, use and storage of such data have potential risks for the exercise and observance of human rights and fundamental freedoms, and respect for human dignity.

It should be emphasized that there is an emerging need for independent international centers of expertise and commissions to verify the ethical and legal aspects of genomic research and the confidentiality of this information obtained from DNA samples from indigenous peoples and local communities around the world. It is very likely that in the near future international jurists will question the need for international legal regulation of such universal health biobanks (Yastrebova and Gulyaeva, 2021) in order to preserve the common heritage of humanity.

Therefore, establishment of a single global registry — a databank of genetic information on the health of indigenous peoples has to be registered with the United Nations General Secretariat by analogy with the law of outer space and the law of the sea.

III. UN Sustainable Development Goals and the Rights of Indigenous Peoples and Local Communities

The goals enshrined in the UN 2030 Agenda for Sustainable Development (UN General Assembly resolution 70/1) include an essential component such as the full protection of indigenous peoples' rights. The UN Permanent Forum on Indigenous Issues²⁰ was established within

²⁰ The Permanent Forum and the 2030 Agenda. Available at <https://www.un.org/development/desa/indigenouspeoples/focus-areas/post-2015-agenda/>

ECOSOC to actively participate in the 2030 Agenda for Sustainable Development and to oversee that indigenous peoples' rights²¹ are implemented first, follow up and review the Agenda itself. As a subsidiary body of ECOSOC, the Permanent Forum contributes substantially to the thematic reviews of the Sustainable Development Goals. Over the years, the UNCSD Permanent Forum has made several recommendations concerning indigenous peoples' conservation priorities, first in the framework of the Millennium Development Goals, then in the so-called Post-2015 Agenda negotiations, in the 2030 Agenda and the Sustainable Development Goals adopted on 25 September 2015.

For example, among the experts is the creation of research infrastructure on indigenous lands, which would allow the extraction of genetic technology "from the obscura" and ensure the transparency of projects. There are also plans to establish an independent genetic research institute, a network of research centers in various indigenous communities with independent biobanks, computing clusters and scholarship programs.

The recent report of the 16th session of the Permanent Forum on Indigenous Issues²² includes a special section with recommendations related to the 2030 Agenda, based on extensive dialogue and discussion with the participants of the 16th session of the Permanent Forum, including indigenous peoples, Member States, UN specialized agencies and other stakeholders. The main recommendations address the following issues:

- paying due attention to indigenous peoples' rights and the UN Declaration on the Rights of Indigenous Peoples in the implementation of the 2030 Agenda;
- establishment of consultative platforms for IPs, and voluntary inclusion of IPs in national reviews at the HLPF;

[the-sustainable-development-goals-sdgs-and-indigenous/recommendations.html](https://www.un.org/development/desa/indigenouspeoples/focus-areas/post-2015-agenda/the-sustainable-development-goals-sdgs-and-indigenous/recommendations.html) [Accessed 24.01.2022].

²¹ Indigenous Peoples and the 2030 Agenda. Available at: <https://www.un.org/development/desa/indigenouspeoples/focus-areas/post-2015-agenda/the-sustainable-development-goals-sdgs-and-indigenous.html> [Accessed 24.01.2022].

²² United Nations Permanent Forum on Indigenous Issues Report on the sixteenth session (24 April to 5 May 2017) Recommendations Specifically Pertaining to the 2030 Agenda adopted by the Permanent Forum on Indigenous Issues.

— disaggregation of data according to indigenous identifiers and inclusion of appropriate indicators for IPs, in particular related to secure land tenure.

The recommendations of the 15th session reflect the implementation of the commitments set out in the 2014 World Conference on Indigenous Peoples' Outcome Document (*World Conference on Indigenous Peoples' Outcome Document*), in which Member States committed to give due consideration to all rights of indigenous peoples when developing the post-2015 development agenda (*paragraph 37*) and generally to work with indigenous peoples to disaggregate data, as appropriate, or conduct surveys and use holistic indicators of indigenous peoples' well-being to address the situation and needs of indigenous peoples and individuals in particular the elderly, women, youth, children and the disabled (*paragraph 10*).

To implement the recommendations, the Secretariat of the Permanent Forum on Indigenous Issues (Division for Social Policy and Development, Department of Economic and Social Affairs) organized an "Expert Group Meeting on Indigenous Peoples and the 2030 Agenda" in October 2015. At the meeting, the experts proposed specific indicators for indigenous peoples' development and how they should be reflected in the review and follow-up of the 2030 Agenda.

The officially published document "**ABS is Genetic Resources for Sustainable Development**"²³ on the UN website notes the impact of the Nagoya Protocol on Access and Benefit Sharing (ABS) and the importance of national ABS laws/policies for achieving the Sustainable Development Goals (SDGs). In particular, the legal framework targets the private sector, researchers, indigenous peoples and local communities from 27 countries to develop innovative products that contribute to the UN SDGs.

This report highlights that genetic resources are accelerators of the 2030 Agenda for Sustainable Development. Genetic resources contribute

²³ This paper deals with biodiversity and how traditional knowledge, science, technology and human ingenuity can be used to develop new products from genetic resources. Witnesses and sustainability advocates provide personal perspectives on the implications of new discoveries in biology, including reflections on key challenges and how to overcome them. Available at: <https://www.undp.org/publications/abs-genetic-resources-sustainable-development> [Accessed 24.01.2022].

to poverty reduction (Goal 1), food security (Goal 2), good health and well-being (Goal 3), gender equality (Goal 5), innovation (Goal 9) and life on earth (Goal 15). In addition, stories of biological discoveries are excellent examples of national and international partnerships (Goal 17). The chapters are written by experts and practitioners from governments, private companies, research institutes, indigenous peoples, local communities and UNDP.

As a result of indigenous peoples' active participation in the 2030 Agenda process, the final resolution "Transforming our world: the 2030 Agenda for Sustainable Development" (A/RES/70/1) mentions indigenous peoples six times, and three times in the political declaration; two of the targets under Goal 2, Eradicate Hunger (target 2.3) and Goal 4, on education (target 4.5), and one in the follow-up and review section, which calls for indigenous peoples' participation.

In addition to explicit references, many of the Sustainable Development Goals and related targets are relevant to indigenous peoples. Moreover, the comprehensive structure of the 2030 Agenda contains many elements that can help to articulate indigenous peoples' development concerns. Importantly, human rights principles and standards are clearly reflected in the 2030 Agenda (A/RES/70/1, para. 10). Moreover, the overall focus of the 2030 Agenda on reducing inequalities is of particular importance for indigenous peoples, who are almost always disadvantaged compared to other segments of the population.

The global indicator framework that will measure progress towards the 17 Sustainable Development Goals (SDGs) includes two indicators that are specific to indigenous peoples (indicator 2.3.2 and 4.5.1) and several other indicators relevant to indigenous peoples, in particular indicator 1.4.2 and 5.a.1 on land rights. Moreover, there has been much emphasis on the need to disaggregate data, as advocated for, *inter alia*, by the UN Permanent Forum on Indigenous Issues. The list of global indicators states that "SDG indicators should be disaggregated, where relevant, by income, gender, age, race, ethnicity, migration status, disability and geographic location or other characteristics in accordance with the Fundamental Principles of Official Statistics." The

Statistical Commission agreed the global indicator framework in 2017 as a voluntary and country-driven tool, but work on it is still ongoing and will be adjusted as necessary in the coming years. At this stage, indicators are being developed at the national and regional levels.

The primary responsibility for implementation, review and follow-up lies at the national level, as outlined in A/RES/70/1. Globally, the High-Level Political Forum (HLPF) is the main UN platform for oversight of follow-up and reporting. **Indigenous peoples have attended both meetings of the HLPF in order to include indigenous voices, priorities and concerns.** The HLPF will meet once a year under the auspices of the Economic and Social Council and every four years under the auspices of the General Assembly.²⁴

In “**Countering Injustice in Genomic Science**” (Guglielmi, 2019, pp. 290–293), researchers call genomics “inclusive,” working with communities that have been ignored or abused. A prime example is the case of a Pacific coastal resident in southern Mexico who decided to trace his ancestry back to the sixteenth century, believing himself to be Afro Mexican. The group is not officially recognized as an ethnic minority by the Mexican government, so members of the community cannot receive government funding for cultural programs. Members of the group have turned to geneticists to find answers to their questions.

Building trust and long-term partnerships with communities is not easy, and many in the field are still struggling to understand how to achieve scientific goals and respect cultural sensitivity. Geneticists are concerned that some still view indigenous peoples as guinea pigs rather than research partners, an egregious approach that Native Hawaiian anthropologist Keolu Fox describes as “*biocolonial*.”

To date, there has been a lack of reliable data and information on indigenous peoples, as well as biopiracy and misuse of their traditional knowledge and cultural heritage. These are the problems that were addressed in the process of drafting and negotiating the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Paradoxically, even with the onset of the global “information revolution,”

²⁴ Resolution A/RES/70/299 adopted by the General Assembly on 29 July 2016. Follow-up and review of the 2030 Agenda for Sustainable Development at the global level (A/70/L.60). Available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N16/241/59/PDF/N1624159.pdf?OpenElement> [Accessed 24.01.2022].

these problems persist in many countries where indigenous peoples live. The United Nations Permanent Forum on Indigenous Issues at its first and second sessions²⁵ (2002, 2003) has already recognized that a key problem facing national and international bodies is the lack of disaggregated data on indigenous peoples.

The lack or scarcity of information on the territory and numbers of indigenous peoples, on how individual and collective rights are being realized, is directly linked to the weakness of the policies of governments and inter-governmental bodies in formulating and realizing the rights of indigenous peoples. Several expert meetings and forum meetings have produced recommendations on how data on indigenous peoples can be collected and disaggregated, and on how and which indicators should be used to measure the implementation of the Sustainable Development Goals, with respect to the realization of indigenous peoples' rights.

Data should be collected to measure compliance with indigenous peoples' rights to access and ownership of lands, territories and resources; how their participation in decision-making and control over their own development processes is progressing; what kind of control they can exercise over data and knowledge; and what discrimination and exclusion they face with regard to their social, economic and cultural rights.

United Nations forums have emphasized that indigenous peoples should control data and that their effective participation in data collection and research should be ensured. Moreover, the resulting data should be available for their use in policy formulation, planning, and monitoring and evaluation. Unfortunately, there is still a long way to go before such data collection and disaggregation is done in most countries outside Canada, Australia, New Zealand, the USA and some Latin American countries.

A common concern raised by governments is the lack of financial and technical resources to undertake this task. Another unfounded fear, repeatedly expressed by some governments, is that creating disaggregated data could exacerbate discrimination and that differentiating data could lead to conflict. Such concerns should not be used to deny indigenous

²⁵ United Nations Permanent Forum on Indigenous Issues at its first and second sessions (2002, 2003).

peoples their right to self-determination (Article 3 of the UNDRIP), which is the freedom to choose their political status and freely pursue their economic, social and cultural development. This right necessarily includes guarantees that the data and information collected by or with them reflects their past and present realities and provides the basis for their aspirations for autonomous economic, social and cultural development. *The concept of data sovereignty* is linked to indigenous peoples' right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as their right to maintain, control, protect and develop their intellectual property over them.

The emergence of a global information revolution and related new technologies can be a double-edged sword for indigenous peoples. If indigenous peoples control how data and knowledge will be generated, analyzed and documented, as well as disseminated and used, positive results can be achieved. Collecting and disaggregating data on indigenous peoples and documenting and transferring their knowledge to younger generations can be facilitated. They can be the main beneficiaries of the use of data, their knowledge and their cultural heritage (Kukutai and Taylor, 2016).

However, if indigenous peoples lose control due to the lack of existing laws and policies recognizing their rights and regulating the behavior of institutions and individuals involved in the collection and dissemination of data and knowledge, marginalization, inequality and discrimination will persist. Respect for their right to obtain their free, prior and informed consent before the data collection and dissemination is crucial to prevent this.

As more businesses and organizations have adopted cloud-based data storage models, this raised concerns about the security and confidentiality of data stored abroad, as well as the legal framework and principles of confidentiality to which these data are subject, including the data problem.

It should be recalled that there are small indigenous peoples in Europe, although not as well-known as the indigenous peoples of the Americas as well as other parts of the world. Like all Europeans, various international instruments guarantee certain human rights to these

peoples but the right of such peoples to live a traditional way of life in Europe is not well established. For complex socio-historical reasons, complaints by indigenous community peoples in Europe are often ignored and communities are not often able to obtain a substantive resolution before the bodies of the European Convention on Human Rights. The lack of substantive resolution of these complaints in Europe stands in stark contrast to the practice of the Inter-American Court of Human Rights (IACHR), where cases affecting indigenous peoples are regularly heard and decided. As a result, the rights of indigenous peoples in the Americas are better and better established (Ruozzi, 2011), while in Europe such rights are hardly mentioned. However, this difference between the European and inter-American systems is not insurmountable, and the Council of Europe can learn from the inter-American human rights system how to defend the rights of indigenous representatives.

There are very few indigenous communal peoples left in Europe today, such as the Saami in Scandinavia, and various indigenous communal peoples in Siberia and northern Russia (Vakhtin, 1994, 2019).²⁶ These groups are small in number, compared to those in South and Central America, where there are now over 800 distinct indigenous groups. The small number of indigenous communal peoples in Europe²⁷ is the main reason that minority rights protection in Europe concentrates on the more linguistically and religiously distinct communities. The difference in the number of cases concerning indigenous communal peoples between the ECHR²⁸ and IACHR²⁹ can be explained by the size

²⁶ In Russia, they, among others, include the Samoyeds, Yakuts, Khantis, and the Manyas. Indigenous Peoples of the North.

²⁷ *G. & E. v. Norway*, App. No 9278/81, 35 Eur. Comm'n H.R. Dec. & Rep. 30 (1983).

²⁸ ECtHR jurisprudence on indigenous peoples: *O.B. and Others Against Norway*, O.B. & Others, App. No 15997/90, Eur. Comm'n H.R. Dec. & Rep., at 8–9. *Könkäma and 38 other Saami Villages v. Sweden*, App. No 27033/95, Eur. Comm'n H.R. Dec. & Rep. (1996), <http://hudoc.echr.coe.int/app/conversion/pdf/?library=ECHR&id=001-3390&filename=001-3390.pdf&TID=THkbhnilzk; Halvar From Against Sweden; Johti Sapmelaccat RY and Others Against Finland; the Muonio Saami Village Against Sweden; Hingitag 53 Against Denmark, Handolsdalen Sami Village and Others Against Sweden; Chagos Islanders Against United Kingdom>.

²⁹ IACHR's jurisprudence in relation to indigenous peoples: *Kichwa Indigenous People of Sarayaku v. Ecuador*, Merits & Reparations, Judgment, Inter-Am. Ct. H.R.

of the population concerned. However, the significant differences in decisions in such cases are not so easily explained. Of the few cases submitted to the ECtHR and the European Commission of Human Rights, almost all were rejected at the stage of determining admissibility on the merits. The complaints did not get to the merits.

IV. International Legal Recognition of Indigenous Peoples' Somatic Rights in Processing of Genetic Information

In contemporary international human rights law, everyone has the fundamental and inalienable right to respect for his or her dignity, uniqueness, uniqueness and non-discrimination on the basis of genetic heritage. The European legal system has established the fundamental principles of bioethics: *respect for dignity, autonomy, integrity, good faith, vulnerability, free and informed consent, responsibility and justice*. Russia has also launched a genetic technology development program from 2019, which runs until 2027, with plans to create full genomic portfolios of up to 250,000 DNA samples by 2024.

The Universal Declaration on the Human Genome and Human Rights³⁰ recognizes the special status of human genetic data as being confidential since they can be predictive of genetic predispositions

(ser. C) No 245 (June 27, 2012); Indigenous Communities of the Xingu River Basin in *Para v. Brazil*, Inter-Am. Comm'n H.R., Apr. 11, 2011, (PM 382/10); *Salvador Chiriboga v. Ecuador*, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 222 (Mar. 3, 2011); *Xákmok Kásek Indigenous Community v. Paraguay*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 214 (Aug. 24, 2010); *Saramaka People v. Suriname*, Preliminary Objections, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 172 (Nov. 28, 2007); *Sawhoyamaya Indigenous Community v. Paraguay*, Merits, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 146 (Mar. 29, 2006); *Yakye Axa Indigenous Community v. Paraguay*, Inter-Am. Ct. H.R. (ser. C) No 125 (June 17, 2005); *Moiwana Community v. Suriname*, Preliminary Objections, Merits, Reparations and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No 124 (June 15, 2005); *Mayagna (Sumo) Awas Tingni Community v. Nicaragua*, Inter-Am. Ct. H.R. (ser. C) No 79 (Aug. 31 2001); IACHR, Report No 96/03, Case 12.053, *Maya Indigenous Communities of the Toledo District (Belize)*, October 24, 2003.

³⁰ Universal Declaration on the Human Genome and Human Rights adopted on 11 November 1997 by the General Conference of the United Nations Educational, Scientific and Cultural Organization. Available at: https://www.un.org/ru/documents/decl_conv/declarations/human_genome.shtml [Accessed 24.01.2022].

concerning individuals and that the power of predictability can be stronger than assessed at the time of deriving the data. Furthermore, it is interesting to note that such data may have a significant impact on the family, including offspring, and in some instances on the whole group, extending over generations; because they may contain information the significance of which may not be known at the time of collection of biological samples; and because they may have cultural significance for individuals or groups.

The generation of somatic rights is regulated by a number of international legal instruments, among which the most important are the following:

- Convention for the Protection of Human Rights and Dignity with regard to the Application of Biology and Medicine, adopted by the Council of Europe in 1997;
- Resolution 2001/39 of 26 July 2004 on “Genetic privacy and non-discrimination”;
- Resolution 2003/69 of 25 April 2003 on “Human rights and bioethics”;
- United Nations Declaration on Human Cloning, which was adopted by the United Nations General Assembly in 2005.

This international instrument has received worldwide support from the international community and has also influenced Member States using it in the development of their legislation, regulations, norms and standards, as well as codes of ethics and guidelines. The provisions of the Declaration state that international and regional instruments, national laws, regulations and ethical texts relating to the protection of human rights and fundamental freedoms and to respect for human dignity as regards the collection, processing, use and storage of scientific data, as well as of medical data and personal data, shall be based on this instrument.

Since the development of innovations today often requires the use of the full diversity of genetic resources, one of the central issues in the current debate is the need to expand the requirement for patent disclosure. There has always been some tension between patent law and biodiversity law, which has often been a source of disagreement.

The Convention on Biological Diversity defines “genetic resources” as “genetic material of actual and potential value” and “genetic material” as “any material of plant, animal, microbial or other origin containing functional units of heredity.”³¹ The latter expression is generally understood to mean that the material must contain DNA (deoxyribonucleic acid) and RNA (ribonucleic acid).

In 2013, the United States Supreme Court ruled that genes cannot be patented since DNA is a product of nature.³² The decision of the United States Supreme Court declared the previous patents null and void making previously patented genes available again. The debate is evolving against the backdrop of the hesitancy of individual states to recognize the significance of the moral and ethical conflict in patenting, which boils down to the following dilemma: one party to the conflict advocates patents and sees this right as protecting intellectual property and ensuring further development of science, while the other party raises concerns about patenting natural objects and respect for the fundamental principles of dignity and integrity of persons.

WIPO developed the Patent Disclosure Requirements for Genetic Resources and Traditional Knowledge,³³ which is a technical study of the current legal and practical issues surrounding the patent disclosure of information on genetic resources. The study identifies specific disclosure requirements for genetic resources and traditional knowledge:

- 1) define the legal status of genetic resources and traditional knowledge, the requirement of legality on mutually agreed terms);
- 2) disclosure of the origin and/or source of genetic resources and traditional knowledge;
- 3) a statement of due diligence in which the applicant reports compliance with all applicable legal requirements for access and utilization of genetic resources.

³¹ Article 2 of the UN Convention on Biological Diversity of 05.06.1992. Available at: https://www.un.org/ru/documents/decl_conv/conventions/biodiv.shtml [Accessed 24.01.2022].

³² US Supreme Court says human DNA cannot be patented. Available at: <https://www.bbc.com/news/world-us-canada-22895161> [Accessed 24.01.2022].

³³ Patent disclosure requirements for genetic resources and traditional knowledge. Main issues. Second edition. 2009. Available at: https://www.wipo.int/edocs/pubdocs/ru/wipo_pub_1047_19.pdf [Accessed 24.01.2022] (In Russ.).

However, it should be noted that human genetic resources are excluded from the scope of application of the UN Convention on Biological Diversity. Such an exclusion is also provided for in the patent disclosure requirements of national legal systems.

On the one hand, the expansion of genomic research and the novelty of the methods used has given a powerful impetus to the development of medical and other scientific research, the diagnosis and treatment of diseases, and the identification of evidence in criminal proceedings. On the other hand, the rapidity of research on the human genome has given rise to a number of problems associated with the specifics of the subject of legal regulation in this area. Since the genome, as a global phenomenon, affects the interests of all mankind and has a special nature of regulation of information obtained in the course of genomic research, the subject of legal regulation in this area is also heterogeneous and constantly subject to transformations. Firstly, the subject under consideration includes relations that directly affect the conduct of genomic studies and their subsequent implementation in various social spheres. Secondly, it includes relations related to the obtaining and further use of information on the human genome (Kalinichenko, 2020).

The rapid progress in genomic developments (genetic editing and gene engineering, genomic testing and genomic registration, genomic screening and monitoring) has also generated ethical problems, which have some peculiarities. First, genomic research involves risks to human life and health. It is important to note that there are particularly acute questions about editing the genome at the embryonic stage. Secondly, any experiments on an individual's genome will affect not only the individual subject, but also their descendants, which also requires special precautions to be taken. Lastly, ethical problems often arise in cases where human genome research is conducted for scientific rather than clinical purposes, that is, research is not directed towards crucial human goals (Yudin, 1998, pp. 242–243).

The regulation of genomic research is primarily aimed at protecting human rights, at carrying out safe activities, and at protecting intellectual property. However, so far there has been no centralized, uniform approach to the regulation of this sphere at the universal level.

The first international document regulating the ethical side of the issue of human research (including research in such spheres as genetics and medicine) was the Nuremberg Code of 1947, which had a recommendatory character. The Code, adopted at the conclusion of the Nuremberg trials,³⁴ is considered to be the first set of rules that established ethical guidelines and standards for research and experimentation on humans (Siliyanova, 2014, p. 85). The Nuremberg Code, for example, made voluntary consent obligatory for medical and other types of research on human subjects. The subject of the research must be recognized as competent to do so and must be informed of all aspects of the research to be conducted (Yudin, 1998, 36–362). In this way, the principle of free and informed consent, which was first enshrined in the Nuremberg Code, has become one of the key documents in bioethics³⁵ in subsequent years.

Another document of great influence on bioethics is the Declaration of Helsinki of the World Medical Association (1964)³⁶ that also has a recommendatory character. This document, unlike the Nuremberg Code, allows for consent to medical research on human subjects, even when the subject is declared incompetent. In this case, consent must be obtained from the legal representative of the subject (Article 28). The 1964 Declaration of Helsinki also established the most important bioethical principle — that the rights and interests of the research subject must take priority over the aims and purposes of the research (Article 8).

Specific provisions of the International Covenant on Civil and Political Rights³⁷ adopted by the United Nations General Assembly in

³⁴ A major trial (1945–1946) where the main war criminals of World War II were convicted.

³⁵ A field of interdisciplinary research aimed at solving ethical problems that have arisen as a result of scientific research.

³⁶ The Declaration of Helsinki of the World Medical Association, 1964. (Revised 19.10.2013). Available at: <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects> [Accessed 05.03.2021].

³⁷ International Covenant on Civil and Political Rights, 1966. Available at: https://www.un.org/ru/documents/decl_conv/conventions/pactpol.shtml [Accessed 24.01.2022].

1966, also address the bioethical side of the research on human beings. This paper emphasizes that it is prohibited to perform medical and other experiments on human beings without their free consent (Art. 7).

Thus, it may be concluded that long before human genome research was actively pursued, bioethical foundations have already been laid for regulating the safety of scientific experiments on human beings and their biological samples. Although the 1947 Code of Nuremberg and the 1964 Declaration of Helsinki of the WMA are nonetheless only recommendatory in nature and pertain primarily to research for medical purposes, they were nonetheless a significant step in the history of bioethics, and all subsequent documents on the subject have been adopted with them in mind. As for the 1966 International Covenant on Civil and Political Rights, it already constitutes an element of international law, thereby establishing provisions for the patient's free consent.

The UNESCO Declaration of 1997 equates the human genome with "the heritage of humanity" (Art. 1) that cannot be "a source of revenue" (Art. 4). Articles 5 to 9 of this Declaration outline the fundamental rights of the persons concerned. These include a mandatory prior careful assessment of the risks and verification of the intended results, the right to free and informed consent (that can also be obtained from others within the framework of national legislation), the right to non-discrimination, the right to confidentiality of the genetic information provided and, in the event of harm, the right to compensation. However, the UNESCO Declaration of 1997 envisages the possibility of limiting the principles of confidentiality and consent where there are "very serious reasons" which are not explained. By analogy, for example, with the 1964 Declaration of Helsinki, the 1997 UNESCO Declaration also states that human rights and freedoms prevail over scientific goals (Art. 10). One of the characteristics of the 1997 UNESCO Declaration is that the person concerned has the right to accept or refuse to be informed of the results and consequences of genetic analysis (Art. 5), that is to say, a person's right to be ignorant.

The instrument is consistent with and supports the objectives of the Convention on Biological Diversity and the Nagoya Protocol, and is not inconsistent with those objectives, including with regard to the

following aspects: (a) consistency with the conservation and sustainable use objectives of biodiversity; (b) fairness and equity in benefit sharing; (c) legal certainty in relation to access to genetic resources or traditional knowledge associated with genetic resources, including, as appropriate, prior informed consent and benefit sharing; (d) full and effective participation of relevant indigenous peoples and local communities; (e) contribution to sustainable development arising from internationally agreed goals; (f) other general principles of law, including good faith and efficiency.

The provisions of the United Nations Declaration on the Rights of Indigenous Peoples³⁸ are important in this regard: “all peoples contribute to the diversity and richness of civilizations and cultures, which constitute the common heritage of humankind.” Furthermore, Member States need to recognize the urgent need to respect and promote the inherent rights of indigenous peoples based on their political, economic and social structures as well as on their cultures, spiritual traditions, histories and philosophies, especially their rights to their lands, territories and resources. Also noteworthy is the need to respect indigenous peoples’ knowledge, culture and traditional practices that contribute to sustainable and equitable development and appropriate care for the environment. Thus, Article 2 of the Declaration stresses that “Indigenous individuals and peoples are free and equal to all other peoples and individuals among them and have the right to be free from any kind of discrimination in the exercise of their rights, in particular discrimination based on their indigenous origin or identity.” Article 31 of the Declaration states: “Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their

³⁸ United Nations Declaration on the Rights of Indigenous Peoples, adopted by General Assembly resolution 61/295 of 13 September 2007.

intellectual property over such cultural heritage, traditional knowledge and traditional cultural expressions.” As can be seen from the text of the Declaration, indigenous peoples are granted a special legal regime for the protection of rights and freedoms.

Attention should also be drawn to the draft Recommendation on the Protection and Use of Health-Related Data.³⁹ The document provides for the importance of adopting a legal framework for the processing of health data. According to the drafters, the Guidelines should provide a common international legal basis for minimum standards for the protection of health-related data, enshrine legal provisions at the national level, and be a point of reference for the ongoing debate on how the right to privacy can be protected in the context of cross-border transfers of health data in combination with other human rights. According to the text of the submitted draft, “genetic data” means all personal data on a person’s genetic characteristics that are either inherited or obtained during prenatal development, since they result from analysis of a biological sample of the person concerned, in particular chromosome, DNA or RNA analysis or any other element that provides equivalent information.⁴⁰ In working on the draft, two questions arose for the experts: (a) should non-genetic information revealing genetic information, such as family history, be included in the definition? (b) should data on somatic tumor mutation, which may not necessarily be considered an acquired characteristic of the individual, be specified. It is noteworthy that “before any data processing, individuals should be informed of the possibility of **not receiving information** about

³⁹ Draft Recommendation on the Protection and use of health-related data T-PD (2017)03. Mandate of the United Nations Special Rapporteur on the Right to Privacy — Task Force on Privacy and the Protection of Health Data the importance of a legitimate basis for data processing of health-related data. The Consultative Committee of the Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data. Available at: <https://rm.coe.int/draft-recommendation-on-the-protection-and-use-of-health-related-data/1680943beb> [Accessed 24.01.2022]. Council of Europe, Committee of Ministers, Recommendation No R(97)5 on the Protection of Medical Data (Feb. 13, 1997). Available at: <http://hrlibrary.umn.edu/instree/coerecr97-5.html> [Accessed 24.01.2022].

⁴⁰ Draft Recommendation on the Protection and Use of Health-Related Data. Available at: <https://rm.coe.int/draft-recommendation-on-the-protection-and-use-of-health-related-data/1680943beb> [Accessed 24.01.2022].

the results, including any incidental findings. The wish not to receive such information may, in exceptional circumstances, be restricted, as provided for by law, in such cases where the doctor has a duty of care or where it is in the public health interest to do so. A person's wish to remain ignorant of a diagnosis or prognosis should be respected, except where this poses a serious risk to the health of third parties. The information that the data subject has a right to know under this provision does not extend to unverified research results, where in an objective assessment granting access could be misleading." The text of the draft is currently being worked on.

Nevertheless, from a scientific and technical point of view, various human genetic materials, including specimens from indigenous peoples, could be used in, or form the basis for, patented inventions. Therefore, some national and regional laws and regulations address the issue in terms of patent disclosure. A prime example is Section 8(b) of the Patents Act No 9 of December 5, 1967 (as amended in 2016), which provides as follows: "Where the invention relates to or involves the use of biological material derived from the human body, the patent application shall include information as to whether the person from whom the biological material was obtained has given his consent to its use under the Biobank Act No 12 of 21 February 2003."

According to the Preamble of Directive 98/44/EC of 6 July 1998 on the legal protection of biotechnological inventions, a distinction is made between biological material of human origin and biological material of plant or animal origin and applicants are encouraged to obtain prior informed consent from the person who submitted such material:

"(26) Where, however, the invention is based on, or involves biological material of human origin, the person from whose body such material was taken should, when filing the patent application, be able to give free and informed consent, subject to the provisions of national law."

V. Conclusion

The author concludes that the relevance of genetic research on indigenous peoples' DNA in the world is growing. The technological revolution makes it necessary to speak of the importance of protection

of personal data in indigenous DNA research in cyberspace, the non-return to eugenics and the necessary adoption of common international ethical and legal standards. The author draws attention to possible future violations of somatic rights in the creation of national and personalized biobanks, genomic sovereignty of individual nations and peoples. There is an urgent need for States and private corporations in the conduct of their business to comply with UN SDGs 2030 and respect the rights of indigenous peoples and local communities as recognized. At present, international law regulates genomic research on the basis of international soft law, which, first of all, relates to the specificity of the subject matter of the area in question. The concept of soft law includes prescriptions by public authorities, which are not legally binding but are social regulators. Soft law plays an important role, as often not only directs the legal discourse, but also provides the framework for strong rules.

The regulation of genomic research is primarily aimed at protecting human rights, at carrying out safe activities, and at protecting intellectual property. However, so far there has been no centralized, uniform approach to regulating this sphere at the universal level.

The establishment of specialized committees to develop international standards for the control of genomic research, as well as the preparation of documents regulating the safety of this research, is carried out at the universal level within the framework of such international organizations as the United Nations (UN), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the United Nations Food and Agriculture Organization (FAO), the World Health Organization (WHO), and the World Health Organization (WHO) and others.

The basic principles for the regulation of research in the field of the human genome are laid down in universal international documents that ensure the protection of human rights, such as, for example: Universal Declaration of Human Rights of 10.12.1948; UN International Convention on the Elimination of All Forms of Racial Discrimination of 21.12.1965; UN International Covenant on Economic, Social and Cultural Rights and on Civil and Political Rights of 16.12.1966; UN Convention on the Elimination of All Forms of Discrimination against

Women of 18.12.1979; UN Convention on the Rights of the Child of 20.11.1989 (Dubov and Dyakov, 2019, p. 129).

The author therefore proposes that States draft a Convention on the prohibition of racial and ethnic weapons. The author concludes that it is necessary to define as an international crime (crime of “genomocide”⁴¹ against indigenous peoples) any illegal actions with the use of modern biotechnology and genetic engineering methods, committed with the intention to destroy, fully or partially, any national, ethnic, racial or religious group as such. For example, in its application to the International Court of Justice in the Nuclear Weapons case, Australia pointed out that the use of biological weapons⁴² would violate “fundamental general principles of humanity.”⁴³ Indigenous individuals must not be subjected to any act of genocide or any other act of violence, and genetic research must respect all internationally guaranteed rights and freedoms, as well as biosecurity measures. Although human genes are not covered by the Convention on Biodiversity,⁴⁴ it should be applied by analogy in the case of the protection of the “genetic” heritage of mankind.

The author points to the need to address the legal vacuum in terminology regarding the concept of “indigenous peoples” and to the importance of making contact, obtaining indigenous consent for genetic studies and ensuring that the tribe is adequately represented in project

⁴¹ A new type of genocide defined as the following unlawful acts: (a) killing members of such a group; (b) causing serious bodily or mental harm to members of such a group; (c) deliberately creating living conditions for a group calculated to bring about its physical destruction in whole or in part; (d) measures calculated to prevent births within such a group; (e) forcibly transferring children from one human group to another. *See* Convention on the Prevention and Punishment of the Crime of Genocide, adopted by UN General Assembly Resolution 260 (III) of 9 December 1948. Available at: https://www.un.org/ru/documents/decl_conv/conventions/genocide.shtml [Accessed 24.01.2022].

⁴² Biological (bacteriological) weapons are the first category of WMD to fall under the universal prohibition that has become a peremptory norm of international law.

⁴³ Australia, Oral pleadings before the ICJ in the Nuclear Weapons case (*ibid.*, § 79).

⁴⁴ 1992 UN Convention on Biological Diversity. Available at: https://www.un.org/ru/documents/decl_conv/conventions/biodiv.shtml [Accessed 24.01.2022].

publications on genetic studies. Genetic epidemiologists point out that it is crucial to be cautious about making results public on sensitive issues such as migration and population mixing (Marzeca, 2017).

Indigenous health on a global scale is determined by the intergenerational effects of colonization and the persistence of unjust social practices and policies of violence, institutional discrimination and racism. Examples of ethical violations (for instance, forced sterilization, act of genocide, gender-based violence, discrimination, and torture) in the history of genomic research and the lack of specific policies and specific governance bodies for indigenous genomic data reflect centuries of colonization, raise legitimate concerns and reluctance of some indigenous communities to join genomic research projects. Health inequalities hamper efforts to address health issues specific to indigenous peoples. The challenge is to ensure equitable conditions for the participation of indigenous people in genomic research and health care. Therefore, indigenous peoples' ability to have access to genomic tools for diagnosis and to have choices in this scientific space is crucial.

It is a serious concern that Indigenous Peoples currently do not have equitable access to health services and resources, to geneticists, and to genomic and genetic research. Furthermore, proponents of genomic medicine should learn from the stories of genetics/genomics among indigenous peoples and think about what is needed to provide the benefits and opportunities of genomic science. The model of such research should be changed with respect for indigenous peoples, their ancestors and future generations.

In addition, researchers have noted the lack of due consideration for indigenous communities, which is reflected in the lack of indigenous scientists, genomic researchers, medical geneticists, genetic counselors, practitioners and staff in research organizations, as well as in the editorial boards of scientific publications. Such capacity is needed to lead genomic research and clinical trials on fair terms.

The most important international instrument in the field of genomic research to date is the Universal Declaration on the Human Genome and Human Rights,⁴⁵ adopted on 11 November 1997 under the

⁴⁵ Universal Declaration on the Human Genome and Human Rights, 1997. Available at: https://www.un.org/ru/documents/decl_conv/declarations/human_genome.shtml [Accessed 24.01.2022].

auspices of UNESCO. The 1997 UNESCO Declaration stresses the need for international cooperation in the field of genomic research in order to meet the ethical and legal challenges posed by scientific research. This Declaration has been reflected in many regional and national legislations.

It should be emphasized that the principles of international instruments are based on the values of humanism and individualism, *i.e.*, the interests of the individual prevail over the interests of society and science. To date, the activities of international governmental and non-governmental organizations are based on the following key principles: 1) respect for human dignity and the right to privacy and confidentiality of genetic data; 2) principle of informed voluntary consent; 3) principle of equality, non-discrimination and fair treatment; 4) prior assessment of risks, results and benefits of research; 5) promotion of international cooperation in the field of genomic development; 6) protection of genetic material of future generations, environmental protection and biodiversity; 7) prohibition of financial gain from research findings.

In this regard, the author of this study calls for the genetic research of DNA samples of indigenous peoples and local communities to comply with international human rights standards, as set out in international instruments and based on the principles of justice, democracy, respect for human rights, non-discrimination and good faith. The author recalls that indigenous peoples have collective rights that are essential to their existence, well-being and full development as peoples. The establishment of a single international regulatory framework and the formulation of an explicit policy by each State that together would balance the potential benefits and risks of genomic and post-genomic technologies. Thus, already at this stage, humankind recognizes the need to move from soft law in regulating the safety of genomic research to the law itself.

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