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THE RIGHT TO BE FORGOTTEN REGARDING GENETIC DATA: A LEGAL AND ETHICAL ANALYSIS

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Abstract: This article investigates an under-discussed provision of the European Union's (EU's) General Data Protection Regulation (GDPR) regarding genetic data, i.e., the right to be forgotten. The debate on this right came from the commerce-related side of data protection instead of the medical side. Thus, this article addresses the implications of the RTBF for the lawful processing of familial genetic data. The article develops a normative, ethically focused principles argument about interpreting genetic data's right to be forgotten. It gives due consideration to autonomy, privacy, and human dignity. It argues that the individualistic approach of genetic privacy materialised through the extreme solution of data erasure is challenging to combine with familial and scientific research interests. The article suggests an interpretation of the GDPR according to bioethical principles and the inclusion of a specific exception regarding genetic data to prevent patients from claiming the right to be forgotten.

Keywords: bioethics, data protection, genetic data, privacy, right to be forgotten

El derecho al olvido en materia de datos genéticos: un análisis jurídico y ético

Resumen: Este artículo investiga una disposición poco debatida del Reglamento General de Protección de Datos (RGPD) de la Unión Europea (UE) relativa a los datos genéticos, es decir, el derecho al olvido. El debate sobre este derecho procede del lado de la protección de datos relacionados con el comercio en lugar de los aspectos médicos. En consecuencia, este artículo aborda las implicaciones del RTBF para el tratamiento legal de los datos genéticos familiares. El artículo desarrolla una argumentación normativa, centrada en principios éticos, acerca de la interpretación del derecho al olvido de los datos genéticos. Tiene debidamente en cuenta la autonomía, la intimidad y la dignidad humana. Sostiene que el enfoque individualista de la privacidad genética, materializado a través de la solución extrema del borrado de datos, es difícil de combinar con los intereses de la investigación familiar y científica. El artículo sugiere una interpretación del RGPD de acuerdo con los principios bioéticos y la inclusión de una excepción específica relativa a los datos genéticos, que evita que los pacientes reclamen el derecho a ser olvidados.

Palabras clave: bioética, protección de datos, datos genéticos, privacidad, derecho al olvido

O direito ao esquecimento em relação a dados genéticos: uma análise legal e ética

Resumo: Esse artigo investiga uma disposição pouco discutida do Regulamento Geral de Proteção de Dados (GDPR) da União Européia (EU) relacionado a dados genéticos, isto é, o direito ao esquecimento. O debate sobre esse direito veio do lado comercial da proteção de dados ao invés do lado médico. Assim, esse artigo aborda as implicações do RTBF para o processamento legal de dados genéticos familiares. O artigo desenvolve um argumento normativo, de princípios eticamente focados sobre a interpretação do direito ao esquecimento de dados genéticos. Ele dá a devida consideração à autonomia, privacidade e dignidade humana. Ele contesta que a abordagem individualista da privacidade genética, materializada através da solução extrema de apagamento de dados, desafia a combinação de interesses familiares e de pesquisa científica. O artigo sugere uma interpretação do GDPR de acordo com princípios bioéticos e a inclusão de uma exceção específica relacionada a dados genéticos para prevenir pacientes de reivindicarem o direito ao esquecimento.

Palavras-chave: bioética, proteção de dados, dados genéticos, privacidade, direito ao esquecimento

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Introduction

The European Union's (EU) General Data Protection Regulation (GDPR)*(1)* has established an updated regime that merges the various principles of the previous EU's Data Protection Directive 95/46/EC*(2)* in a new full "right to be forgotten" (RTBF). The Right to Be Forgotten (RTBF) is a legal rule enabling individuals to request the removal of their data from online platforms and search engine results, among other archives. It emphasises privacy rights, empowering people to control the dissemination of their personal information. The concept has a global influence, shaping data privacy laws, and aims to strike a balance between privacy and freedom of expression. It allows individuals to manage their online reputations and safeguard their digital identities.

Enshrined in Article 17 of the GDPR, the RTBF has been widely debated, especially in Europe and the United States of America (USA). Different perspectives, such as social, technological, and managerial*(3-14)*, provide a valuable critical reflection on the problems that arise when one of the memory functions—forgetting—becomes difficult in a technological environment*(15,16)*. Although these perspectives provide relevant information on the issue, they fail to adequately address the legal and ethical questions raised by the RTBF regarding health data in general and genetic data in particular.

The debate on this right came from the commerce-related side of data protection instead of the medical side. Although Article 17 already considers a balance of interests (familial ones included) in deciding whether to give effect to the RTBF, it is necessary to conduct an ethical analysis of the problems posed by this law. The medical setting should consider autonomy, privacy, and human dignity. Consequently, there is a central research question: what are the implications of the RTBF for the lawful processing of familial genetic data? Hence, this article's principal focus is making a normative, ethically focused, principled argument about this law's interpretation regarding genetic data. To this end, we will address health and genetic data privacy and protection. We will elaborate on our reflection by specifying the actors involved in processing genetic data, what genetic data is, and how genetic data relates to individuals' relatives and groups. Also, how genetic data are, or are not, different from health data, and how the processing of genetic data works in various contexts. We will conclude our discussion by considering the underlying bioethical principles that should support assessing how information can *be forgotten* in medical genetics [emphasis added].

Genetic privacy, the right to be forgotten, and human dignity

Health information general background

Formerly, health data were shared and collected in a relational context of proximity and trust. Because this data category is sensitive from a privacy standpoint, health information protection has always presented many legal and ethical issues. The fact that health data are intimate comprises one explanation for why it is reasonable that access to the medical profession implies a symbolic oath and establishes a fundamental principle in medicine: secrecy as a condition of respect for autonomy and privacy. The commitment of Hippocrates is still relevant today*(17)*, despite some arguments about the need to reassess the oath in light of modern medicine*(18)*. As quoted by Kayaalp*(19:8)*, it states: "Whatsoever I shall see in the course of my profession, [...] I will never divulge, holding such things to be holy secrets."

However, the generalisation of the registration and archiving of health information and genetic data in computerised databases and the sharing of this information for research purposes expanded the problem of health and genetic data protection. Thus, complex ethical and legal issues emerge —and more so because of a paradigm shift in the last decades. Indeed, in the past, in many jurisdictions, medical records were considered the physician's written memory. However, nowadays, medical information and medical records, including genetic data, are patient data*(20-27)*.

There are several types of personal data in the field of medicine: (a) data voluntarily provided or shared by data subjects, such as medical information transmitted to the physician or other professionals such as geneticists; (b) observed data collected through an epidemiological study, for instance; and (c) one can deduce trends and generate behavioural and personality profiles by combining observation and analysis of voluntary data and derivatives, derived or inferred data*(28)*, as in human research, clinical auditing, and service evaluation.

Personal data concerning health are embodied in the GDPR as a particular category. Edward S. Dove*(29:1021)* reminds us: “In the health context, “special category” personal data includes data that reveal racial or ethnic origin; data concerning health (the physical or mental health of a person, including the provision of health care services); data concerning sex life or sexual orientation; and genetic and biometric data, processed to identify a natural person uniquely. Genetic data is personal data relating to a natural person’s inherited or acquired genetic characteristics that give unique information about that person’s physiology or health and results, particularly from an analysis of a biological sample from the natural person in question.”

Accordingly, personal health-related data is not necessarily derived from the person directly, which brings us to the discussion of genetic data below.

Genetic data definition and context

According to Taylor*(30)*, genetic data is challenging to define, so he broadly uses the concept to include many different categories of data, each capable of having different types of personal information that can be described as “genetic information”. Taylor argues that this description of genetic data allows for exploring a specific position on the concept of ‘personal data’ best illustrated in the context of genetic information. According to this specialist, such a position on privacy protection depends on recognising a particular relationship between data and information concepts. This author describes information as a “composite concept”, “dependent on a specific interpretive structure applied to the data”*(30:52)*. Accordingly, it is necessary to understand the meaning of explanatory structures in the relationship between data and information to comprehend the restrictions associated with the existing protection of privacy in the law. Hence, Taylor argues that genetic data frequently and acceptably can be placed into various alterable interpretive structures, reminding us*(30:4)*: “The same genetic data might be understood in different contexts and periods to provide information about many other things relating to different persons. This interpretive potential of genetic data helps demonstrate the limitations of the current regulatory system and understand a multitude of different preferences that might be expressed regarding its access and use.”

The Article 29 Data Protection Working Party*(31)* has also published a Document on Genetic Data, noting that these data can be described as having several distinctive features*(31:4-5)*: “Genetic information is unique and distinguishes an individual from others; it may reveal information and have implications for the blood relatives of this individual (biological family), including those of future generations; genetic data can characterise a group of people (*e.g.,* ethnic communities); genetic data may reveal family relationships; genetic information is often unknown to the owner; it does not depend on the individual will of the holder, as genetic data is not modifiable; genetic data can be easily obtained or extracted from the raw material; given scientific development, data may reveal more information in the future and be used by an increasing number of interested parties for various purposes.”

These features highlight critical aspects. Not all genetic data have the same characteristics. When genetic data can be uniquely associated with an individual in one scenario, there may still be associations with others in other situations, which means that a minimum of genetic information can be described as related to a single individual in all conceivable informational environments*(30)*. Therefore, genetic data processing works in various contexts and refers to individuals’ relatives and groups, resulting in ethical difficulties in protecting them*(32)*. Similarly, Graeme Laurie*(33:2)* points out: “It is a fact that genetic information relates to a group of persons and not simply to one individual, which sets genetic information as a class apart from other forms of medical information.” As such, genetic data is different from other types of health data. Genetic data relates to individuals’ relatives and groups, as Laurie*(33:2)* reminds us: “This requires us to consider the group dynamics of managing and controlling shared information and the possible rights and interests that flow from a ‘group’ claim to familial data. These, in turn, must be seen in contradistinction to the more traditional atomistic, autonomy-based approach, which focuses on the individual’s rights and interests from whom the genetic information initially has been obtained.”

At this point, the actors involved in processing genetic data are established in clinical and research settings—for example, within the framework of national and private healthcare databases for clinical, therapeutic, and varied medical purposes, from medically assisted reproduction to biobanks for DNA analysis. Also, there are many genetic information types, such as the results of a simple genetic test, whole-genome sequence data, genetic information valuable from a clinical or research standpoint, information helpful for forensic purposes*(34)*, and sensitive genetic information. ‘Genetic data’ is defined in Article 4 of the GDPR*(1)*. Accordingly, it means “Personal data relating to the inherited or acquired genetic characteristics of a natural person gives unique information about the physiology or the health of that natural person, which results, in particular, from an analysis of a biological sample from the natural person in question.” This notion encompasses every type of genetic information, all of which are included in this discussion. However, Dove*(35:163-164)*, in a pertinent remark, stresses: “This is an unduly narrow definition, given that most genetic data does not provide “unique” information about a single individual but rather, quite often, the individual’s genetic family members. This definition does align, however, with the law’s general fixation with the individual (“data subject”) rather than familiar or group protections, whether for privacy violations, discrimination, or otherwise. […] It may be that those responsible for the collection and use of these data will err on the side of caution and assume that all genetic data should be treated as a category of personal data for the GDPR, even if they do not provide “unique” information about the physiology or the health of an individual (though whole genome sequence data would qualify on uniqueness grounds). If this happens, most research data would be covered by the legal provisions speaking to “genetic data”, even when they might not be truly “unique”.”

Genetic data and research

A critical point in the current governance of genetic data is that large amounts of this data are generated in genetic research. The broader scientific community mandates scientific journals to publish anonymised patient data in online repositories for researchers’ use. Nevertheless, simple crosschecks of personal data or personalised samples could result in patient re-identification in such databases. Therefore, as regards the sharing of the research results, it does not seem acceptable to assume the consent of data subjects, according to the principle of purpose limitation – Article 5, point 1/b) of the GDPR*(1)*– because the purpose is not the same for which they were first collected. Salokannel, Tarkkala and Snell*(36:1287)* present a similar argument regarding Finnish biobank practices: “Ambiguous interpretations of international Regulation—such as the European Convention of Human Rights, the Oviedo Convention, the European Charter of Fundamental Rights, the GDPR, and the EU Clinical Trials Regulation—undermine the autonomy of individuals by not giving individuals a right to consent or an actionable right to opt-out of the transfer of these legacy samples to the biobank.” Sharing research results entails a similar problem because it can easily lead to re-identification. According to Article 89, point 1 of the GDPR, this contradicts the anonymisation of genetic data that justifies its exception treatment for research purposes. The right to be forgotten is an essential part of this setting, which is much more unlimited than the purposes justifying the processing of genetic data.

Research has always relied on data to fulfil its goals. However, access to genetic information for research proved problematic in the past. Regarding the right to be forgotten, the question is not whether personal data is identifiable, pseudo-anonymised, or anonymised. This new right poses a different challenge: the GDPR establishes that personal data can be processed for scientific purposes (freedom of expression, public health interests, and historical or statistical research). However, it does not delineate limits on the right to be forgotten. Patients might have the right to delete genetic information if the data is no longer required for their collected or processed objectives. Patients can withdraw consent under the right conditions (Article 17 of the GDPR). With these remarks, we do not aim to suggest that consent is the only means to process personal research data lawfully. Likewise, anonymisation is one of many legal solutions. Processing personal data can be lawful in the right circumstances. According to Edward Dove*(29)*, consent and anonymisation are only sometimes required (or sufficient to deliver adequate protection). Indeed, as Dove*(29:1021)* points out: "In European data protection law, consent is only one of several legal bases for processing personal data. In other words, researchers who seek to collect and use data from patients and participants may *not* need to rely on consent as their legal basis. Also, *consent is often not the most appropriate lawful basis* in research, particularly in large-scale epidemiological or genetic studies."

Other legal bases for processing sensitive data and processing data for scientific research purposes are exemplified in the GDPR. A relevant exception is Article 9*(2)* (j), i.e., the processing is necessary for scientific research following Article 89*(1)*, and appropriate safeguards are provided. However, the co-existence of the GDPR's provisions on the legitimate processing of genetic data for research purposes and the right to be forgotten without limits regarding research besides Article 89*(1)* does not help us to find a legal solution to prevent claims from the data subject to obtain from the controller the erasure of genetic data. In other words, the GDPR conditions concerning the processing of 'special categories' of personal data (i.e., one of the six legal bases defined in Article 6, plus at least one of the ten exceptions outlined in Article 9*(2)*), combined with the provisions of Articles 17 and 89*(1)* are not especially helpful for scientific research in genetics. The need for more requirements for this matter is a weakness in the legislation. We suggest falling back on ethical values and principles to inform our interpretations of the law. Moreover, the international instruments about genetic data give additional assistance in navigating the legal scenery, as we explain in the next section.

Genetic data and the right to be forgotten

The desire to delete genetic information is relevant because privacy problems strike the field of genetics with particular fervour. Indeed, developments in molecular biology and the sequencing of the human genome have allowed for the progression of predictive medicine. Genetic studies enable researchers to foresee the manifestation of a disease before its signs are evident, allowing the implementation of preventative and precautionary measures through genetic intervention*(37)*. Moreover, the specificity of prediction afforded by modern genetics to genetically determined diseases and susceptibilities toward developing a disease—and even to physical or psychological characteristics in the context of prenatal or preimplantation diagnosis*(38)*. Furthermore, evaluating the subject (index case) allows for the inference of relatives' genetic traits, which may create complex ethical dilemmas, as they are based primarily on the knowledge of sensitive personal and private information. Genetic information gathered from the index case can prove helpful, particularly to relatives.[4]

Aware of the ethical dilemmas that scientific progress in genetics has fomented, the international community, especially within UNESCO and the Council of Europe, has repeatedly set up a collection of declarations, conventions, and recommendations, which indicate general norms to ensure protection in this matter.

The Universal Declaration on the Human Genome and Human Rights proclaimed the Human Genome Common Heritage of Humanity. It reaffirmed respect for all people's dignity and human rights regardless of their genetic characteristics*(39)*. It also ensured 'respect for each individual's right to decide whether to be informed of their genetic exams' results, thereby forming the

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[4] At this point, it bears emphasising that a clear distinction exists between the deletion of data about the human genome and the deletion of the human genome itself. The reader should know that the former is different from the latter, which relates to genome editing. These scenarios raise entirely different legal and ethical questions.

right to informational self-determination. Later, the General Conference of UNESCO unanimously adopted the International Declaration on Human Genetic Data*(40)*. Its primary objective was to respect human dignity and protect human rights and fundamental freedoms in collecting, treating, using, and conserving human genetic data while simultaneously defining the guiding principles for nations in formulating their legislation and policy.

Furthermore, privacy and the right to information are highlighted in the European Convention on Human Rights and Biomedicine*(41)*. Indeed, due to the unauthorised use of personal genetic information in different contexts (*e.g.*, employment, insurance, and education), a *right not to know* (RNTK) [emphasis added] emerged in genetics to protect personal privacy and integrity. In many circumstances, the genetic information was used against the subject's interests in a clear violation of fundamental ethical principles of respect for autonomy and beneficence*(42)*. Moreover, the index case's genetic information was sometimes transmitted to family members without proper consent, even though relatives might benefit from the data*(43)*.

According to Graeme Laurie*(44)*, the Council of Europe and other international bodies have extended patients' rights based on autonomy — the right to know — and the right not to know. Indeed, the Council of Europe's Oviedo Convention on Human Rights and Biomedicine*(41)* illustrates this assertion in article 10*(2):* "Everyone has the right to know any information collected about their health. However, the wish of an individual not to be so informed must be observed." On the other hand, the UNESCO Universal Declaration on the Human Genome and Human Rights*(39)*, in Article 5, stipulates, "The right of every individual to decide whether or not to be informed of the results of the genetic examination and the resulting consequences shall be respected."

Therefore, most national and international legal systems consider self-determination central to patients' rights. Autonomy has conquered a determinant space in the medical-legal sphere, and this concept still characterises legislation governing patient and health professionals' relationships. The law and professional practice have recognised the importance of respect for the patient's autonomy, informed consent, the right to know, and the significance of the right not to know.

The international instruments about genetic privacy, especially the right not to know, are critical in this analysis because they help us understand the difficulty of articulating individual rights with others' rights, especially family members. Therefore, the RTBF's interpretation needs to consider the rights of third parties and the RNTK, which we will discuss.

The right to be forgotten and the right not to know

From a merely individualistic perspective, it could be argued that, as framed in Article 17 of the GDPR, the right to be forgotten and the right not to know—broadly debated in literature as the right not to be informed/appraised of health and genetic information*(45,46)*—share a common perspective. Both rights might be regarded as conditions of autonomy and control*(28,47)*; however, they might have different moments of applicability. Indeed, it is essential to recognise material differences in the scope, content, and application of the two rights. The right not to know is also applicable in the circumstances before the generation of knowledge, *e.g.*, concerning, for instance, avoiding children's genomic testing for late-onset conditions due to the child's right not to know. In this case, the position of ignorance might not be preserved by erasure. If data have been produced, they have been processed before the effective exercise of a right to erasure. However, Roberto Andorno recalls Laurie's argument that besides "autonomy," the right not to know might be grounded in the concept of 'spatial privacy', which is likely to offer more protection for the interest in not knowing when no obvious choice has been made*(47)*. Laurie's argument leads to the following conclusion stated by Andorno: "Even if no wish has been expressed, the interest in not knowing can also be compromised by unsolicited revelations of genetic information"*(47:437)*. In other words, everything changes from the moment information is registered, regardless of the means. The right not to know is not guaranteed following the availability of information. Seen merely from an individualistic perspective, the right to be forgotten goes further than the right not to know. Undeniably, the data subject's right not to know is fully covered if the information is deleted. In this context, the right to delete genetic data looks more robust than the right not to know. Accordingly, from an individualistic standpoint, the right to be forgotten might be considered an evolution of the second, provided the data are no longer required for the purposes for which they were collected or processed. Also, data subjects can withdraw consent in the right circumstances. In this sense, self-determination information seems enhanced*(28)*.

However, the answer becomes more challenging when adding family members' interests and rights concerning familial genetic data. Indeed, the right to be forgotten might compromise the informational self-determination of family members, i.e., their right to know. Similarly, if data are deleted to protect the right to be forgotten, it could harm them and their family members in the future. Considering the paradigm example of Huntington's disease, it can be argued that family members have the right not to know because, currently, nothing can be done about it. Therefore, this might generate an obligation for third parties not to inform the family members (a 'right' not to know). However, it does not follow that the subject's or the family members' interest in not knowing will endure indefinitely. Indeed, if a treatment comes along, this generates good reasons to know and, hence, to disclose.

At this point, it bears emphasising that the individualistic approach to the right to be forgotten can give rise to ethical considerations, as we explain further. However, before that, let us turn to some legal analysis about the nature of the RTBF, which might help us bridge the topic to a more philosophical position on the validity (or not) of this right regarding genetic data.

The legal nature of the right to be forgotten

The literature has tried to present the character of this new right. For instance, Andrade*(48)* suggests that the right to be forgotten is closely related to identity, referring to how individuals project into society. This author states that the right to data protection does not represent the protection of any value or interest in itself. It only establishes the procedures for respecting the values underlying other rights, such as the right to privacy and identity, which derive from two fundamental rights: dignity and self-determination. He argues that identity protection is grounded in the underlying right to data protection rather than privacy, as it concerns transmitting information to the public sphere—that is, the correct projection and representation of one's identity to the public*(48)*. In this sense, the right to be forgotten is an identity condition.

On the other hand, Costa*(49:131)* suggests: "[...] Science cannot directly undermine our sense of self, but it can indirectly affect our self-understanding by providing information that may radically upset our current reflective equilibrium." This argument advocates that data mining and other forms of connecting personal data can undermine our sense of self. Likewise, it might prove that the right to be forgotten protects personal identity.

According to point (a) of Article 6*(1)* and point (a) of Article 9*(2)* of the GDPR, the right to be forgotten is admitted when data are collected through consent subsequently withdrawn and where there is no other legal ground for the processing. Bearing in mind the right to be forgotten as a condition of identity and the subject's individualist perspective about health data, at first sight, these data might be erased as long as it is the person's will. As established in European culture and legislation, patients seem to have the right to eliminate their health information following Article 17 of the GDPR. In this context, any data that can unveil a *self* that the holder does not want to project to society could be subject to the right to be forgotten [emphasis added]. Consider the case of a transgender person who, after gender-affirming surgery, obtains the gender transition legal recognition on the ID document (as is the case in several European countries). They may wish to delete the confirmatory clinical record of performing a trans masculine chest/top surgery and all the tests before it, which unequivocally relate them to a gender they do not want to integrate into society*(50)*. They may not ask to forget their past, nor entirely be *forgotten* as if they had not existed [emphasis added]. Instead, by deleting some clinical records, they might gain better control over the story they tell or the story that might be said about them. Thus, the right to be forgotten is a legal instrument designed to maintain their ability to construct, edit and update their identity*(51)*.

Conversely, let us assume that before the surgery, a genetic test was performed for breast cancer. If this transgender person had a daughter, there might be other legal grounds for maintaining these data, namely the daughter's right to know. In contrast, the right to be forgotten of the transgender can form an effective way of accomplishing the information self-determination that protects their right not to know. It would constitute a more challenging, more robust version of the RNTK.

At this point, it is essential to highlight that consent can be necessary for exercising the RNTK, specifically regarding genetic research results. Indeed, as Knoppers*(52)* recalls, the consent process of genetic research demands researchers to explain the kinds of results that may be exposed so that participants can make informed choices about whether they wish to receive information about themselves. Also, they express preferences about whether the information will be shared with biological relatives or others with whom the participants have a family, community, or group relationship.

Given the above, the current framework of the GDPR does not protect an individual right to have genetic data erased just because the data subject wishes. However, the same framework needs to be more explicit about including genetic data in the exceptions of Article 17 to support the protection and promotion of the broader interests of family members in maintaining such data, and we argue that their rights deserve protection. Accordingly, the international instruments about genetic data (abovementioned) bring us some assistance in the interpretation of this matter, but, in our view, it is also necessary to look beyond the law to bioethical principles to help us think through the challenge as to how the law should be understood. Let us turn to the arguments that might help us with this task.

The right to forget genetic data, human dignity and bioethics

With the Universal Declaration on the Human Genome and Human Rights*(39)*, genetic data became the patrimony of humanity, especially in its intangible dimension, regarding the information it contains about the human species. Indeed, the human genome is the common heritage of humankind, and its genetic data form a repository of individual and collective identity that is, in this sense, inalienable and must be protected*(53, 54)*. The legal argument that directly challenges the GDPR's right to be forgotten is that unavailable rights are involved; thus, genetic data are not at the individual's disposal to invoke a right to delete. From a legal standpoint, looking at genetic data as humankind's common heritage does not obscure the idea that individuals should also have rights over that data. However, in some cases, including the right to have that data erased could be problematic because genetic data are a condition of identity (as discussed above). The right to the human genome must have a particular protection since its purpose is to safeguard the integrity of the human species and the dignity and rights of each of its members. So, the right to the genome is inseparable from the person. It is an essential, inalienable and imprescriptible right*(55)*. What stands out here is the particular interest of humankind despite its occasional collision with individual rights.

Similarly, ethically, the completeness of genetic data is part of human dignity. Deleting information about the human genome is different from genome editing. Yet, protecting a person's genetic data as a unique human means respecting said uniqueness. Consequently, the protection of the human genome is a responsibility for future generations*(56-59)*.

From a legal view, it could also be argued that data reflecting the essential core of personal identity embodied in personal history—the right to memory—should not be dependent, from the perspective of privacy or legitimate interests' protection, on the volatility of a social or political truth of a given moment in time and history. Indeed, supporting the right to delete genetic data might constitute a violation of the informational self-determination of other parties (*e.g.*, the relatives' right to know), as regards not only personal identity (*e.g.*, genetic roots) but also medical reasons (*e.g.*, genetic diagnosis, reproductive choices).

From a legal perspective, we sustain that the right to be forgotten regarding genetic data is problematic because it represents a way of defending, in practical terms, the right not to know as an absolute right. No such rights exist because a necessary balance between them must be accomplished. If we follow Laurie's*(60)* position that the right not to know is a means to defend the right to privacy rather than autonomy, it has legal protection but is not an absolute right. Exceptions are admitted. There will be exceptions where it is justified (in terms of proportionality) that the right colliding with it prevails, particularly in genetic data. In genetics, several people share the data. Therefore, ensuring the individual from whom the information was initially obtained has a right to erase a particular genetic result is not permissible because it also affects people sharing that data. Accordingly, the ethical and legal principles that sustain the argument that there should be no right to be forgotten concerning genetic data are privacy-based, as autonomy has difficulty safeguarding the rights of people who share genetic data*(60)*.

On the other hand, in some cases, the current legal framework and the need to verify genetic data are ethically problematic because anonymisation is one of the measures to ensure the exemption to process genetic data for research purposes*(61)*. Anonymisation is required from the data controller, which is highly challenging to accomplish with this data type. Indeed, Laurie*(60:115)* stated, "Unlike conventional health information, genetic information cannot be completely anonymised. It is a unique marker pointing the way to a single individual."

Different parties' rights and interests should be balanced because the right to delete genetic data should be regarded as ethically problematic. However, we do not defend the idea that genetic data, when not framed in informed consent, serve society's interests *tout court*, without articulating the existing values according to proportionality criteria. A strict utilitarian perspective (the wishes and interests of individuals lose importance for the benefit of all) contends that individual sacrifices are justified through an economic or quantitative perspective; that is, the sacrifice of some individuals is tolerable for the sake of a greater common good*(62)*. Such a perspective remains challenging to accept in a pluralistic society. The civilisation stage of humanity is based on a fundamental value: each individual's human dignity *per se*.

As David Lyon suggests, it is easy to recognise that there are many technological and legal responses to the problems of today's societies, which he characterises as "surveilled"*(63-66)*. We agree with this author when he argues that many studies on data protection need to pay more attention to ethical considerations. This argument urges future researchers to analyse the ethics embedded in the different constituents of *big data* culture*(66)*. Various data combinations seem endless; critical ethical issues await innovative responses encouraging policy agendas and legal measures. As Shi and Wu*(67)* suggest, genetic privacy can advance through ethics education, bolstering privacy regulation.

Conclusion

This article has set forth a legal and ethical assessment of a law that allows deleting specific data – the so-called *right to be forgotten* (RTBF) [emphasis added]. The legal discussion addressed its impact and analysed the implications of implementing this right, including its applicability specifically to genetic data. To this end, we specified the actors involved in processing genetic data, what genetic data are, and how genetic data relates to individuals' relatives and groups. Also, how genetic data are, or are not, different from health data, and how the processing of genetic data works in various contexts. Throughout the discussion, we examined the legal nature of the RTBF, which led us to understand that the literature is divided insofar as it, a data protection right, may be related to privacy, autonomy, and identity personhood. The international instruments about genetic privacy, especially the right not to know (RNTK), were considered critical in the legal analysis because they helped us understand the difficulty of articulating individual rights with others' rights, especially family members' rights. Therefore, the study of the RTBF was framed with the rights of third parties and the RNTK.

The legal analysis conclusion is that the GDPR needs to be more explicit about establishing concrete limits to the RTBF regarding special categories of personal data. However, these data types can be processed in identified cases (*e.g.*, in cases of freedom of expression, public health interests, and historical, scientific, or statistical research). Consequently, the legitimate reasons to process personal data might be jeopardised if a right to delete health and genetic information is granted to individuals. Also, considering the familial claims to genetic data and presuming that a valuable genetic data set exists in which a range of family members might have interests, the current framing of the RTBF does not allow the data to be erased simply because the index case, so wishes. Nonetheless, this right's limitations only partially support the data's retention to protect and promote family members' broader interests. In other words, despite considerable limitations on the RTBF, the law must still be sufficiently forceful to accommodate familial interests. Therefore, we should look further than the law. Bioethical principles help us think through the challenges, both as to how the law should be interpreted and, eventually, conclude that it is better to make this matter more transparent through the inclusion in the GDPR of a specific exception regarding genetic data.

The legal analysis also led us to sustain that the individualistic perspective of genetic privacy that could materialise through the extreme solution of data erasure is challenging to combine with the interest underlying scientific research. The GDPR conditions concerning the processing of "special categories" of personal data (i.e., one of the six legal bases defined in Article 6, plus at least one of the ten exceptions outlined in Article 9*(2)*), combined with the provisions of Articles 17 and 89*(1)* are not especially helpful for scientific research in genetics. The need for provisions for this matter is a weakness in the legislation.

From an ethical standpoint, our analysis led us to reason that legal regulation, although based on fundamental human rights set in bioethical principles, needs help to keep pace with the rapid changes in modern society. Accordingly, individual genetic information presents new challenges. Ethics that exploits the concrete consequences of the era of *big data* are essential. Therefore, humanity's challenge is to redraw itself by confronting technology, institutions, and regulation through ethics. It is crucial to balance scientific/technological progress and human rights. Ultimately, however, the interests of the human being must prevail. Human dignity must remain an undeniable value. Therefore, international institutions, such as UNESCO, might be forced to intervene to establish the necessary framework of action and promote the discussion of this subject to ensure that genetic data are not erased/deleted, as that is ethically challenging.

Thus, the interpretation of the RTBF should look at bioethical principles, and the GDPR should include a specific exception regarding genetic data to prevent patients from claiming the right to be forgotten.

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Ethical approval

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