
Editorial

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1 Is genetic privacy an individualistic right after all?

At the core of the constitutional and philosophical debate, privacy is sometimes considered to be an individualistic right. Thus, a right exclusively orientated in protecting the private goals and aspirations of the individual. In that context, privacy bears an unsocial, narcissistic meaning, which is setting apart the subject from society or even from its intimates. As it has been supported, privacy in this perspective is not a right worth of constitutional acknowledgment or value, but a protective veil, an asylum for the subject to adopt illegal activities or cover unsocial endeavours.

Nevertheless, as far as genetic privacy is concerned the term ‘individualistic’ can be highly contested. The right to genetic privacy is considered to be quite new, since it is connected to the relatively recent technological evolution of decoding the human DNA. The right to genetic privacy brought forward a new aspect of the human self, a rather comprehensive and peculiarly, not individualistic one. The human genome contains not only the information based on which we are distinguished from the others but also the information that define our roots, our family heritage, our parental co-belonging. From this point of view, the right to genetic privacy sets a question mark: to whom our genetic decisions lie with, to what extent can we consider them a ‘private matter’ when our

human genome contains information that we share with our parents, siblings, ancestors and predecessors. In two words, having a right to genetic privacy does or does not give the subject the autonomy to drive its genetic identification by his/her own will?

Let us get acquainted with the 'shared' privacy that the human genome entails using two uneven paradigms. In the case *Paulík versus Slovakia* (European Court of Human Rights (ECHR), Decision of 10.1.2007), the ECHR handled the following circumstances: the applicant had a sexual encounter with a woman in 1966, who gave birth to a daughter on December 17th of the same year. The applicant denied his paternity and the mother of the girl pursued him in the national courts, which asserted his paternity based on a medical test known as 'blood hereditary test', a sexology report and several witnesses. Consequently, the applicant was legally acknowledged as the biological father of the girl in 1970 and supported her financially ever since. To a certain point and when she was a teenager, the applicant started to develop a personal bond with her, which evolved in a familial relationship. At 2004, the applicant and his daughter quarrelled over a financial subject.

The quarrel led them to take a DNA test which proved without any doubt that he was not her biological father. The applicant turned to the national courts which insisted on the 1970 decision on the grounds that the legal acknowledgment of his paternity was in fact irreversible (*res juridicata*). Thus, they denied the applicant's wish to cut any legal, biological or material relationship with his legal but not biological daughter. The applicant then applied to the ECHR in order to protect his right to privacy under Article 8 of the European Convention of Human Rights.

This legal, real life scenario underlines several observations connected to genetic privacy. The applicant's right to his identity, thus his privacy, has been severely inflicted because he has falsely adopted the qualities of a father. The *Paulík versus Slovakia* case not only points out the importance of the genetic evolution regarding the individual's self-determination but also the close connection between our biological and our moral identity. The applicant, Paulík, was imposed with an identity that he did not select: the powerful and symbolic identity of a father. Regardless the actual ties that he developed with his legally acknowledged daughter, what mattered the most was the biological truth of the physical bond connecting them as parent and child. Thus, genetic privacy is a matter of individual privacy, of personal identity and of choices for the subject. But it is also a matter of intimacy, of connecting and co-belonging in a biological and material sense. Not only Paulík but also his daughter was inflicted in this sense. She also had to bear the symbolic identity of the daughter and to suffer of a broken familial bond. What was violated was their shared right to their genetic heritage and their biological family ties.

The second paradigm is much more fetched. It concerns the case of Roche and De Code Genetics Inc., which in 1998 unveiled a scheme for entering all medical records of Iceland into a database, in order to conduct population genomics research by effectively simulating a population. Under the 'Health Sector Database' Act, the Icelandic parliament issued the license to create of a genetic database called 'Icelandic Healthcare Database' (IHD) to Roche and De Code Genetics Inc., which aimed at decoding genomically hereditary diseases. The public genetic scheme of Iceland was in fact an extensive genetic experiment on the whole population. Why was Iceland selected by this American Incorporation in order to perform this vast genetic research? Iceland is a small country of approximately 300,000 inhabitants. It is originated from the 8th A.C. century, from a small colony of Vikings and their Irish slaves. Since then a total of

approximately 850,000 inhabitants have lived in the island-country. There are complete genealogical files for about 600,000 of them, enabling each Icelandic citizen to trace his/her ancestors back to even a thousand years in many cases. This highly ambitious experiment was based on the public healthcare structure of Iceland organised very well by a file-system, as well as on the fact that the population bore 'familial' characteristics. Iceland was in fact a closed society with the minimum amount of immigrants and mixed families.

What was in fact the key to the success of the 'Icelandic experiment' is that this whole nation could indeed be considered as a 'family tree'. Thus, it presented an excellent field for researching hereditary diseases and analysing the DNA of the population. The 'Icelandic Experiment' projects a macro paradigm of the relation between the genetic identity of the individual and its family, its intimates. In the case of Iceland, the common culture and common genealogy could unveil genetic information for a whole nation, consequently. In the Icelandic case, the question posed from the beginning is magnified. Is genetic privacy, an individualistic right or a 'shared' right? Indeed, how complex can the role of the autonomy of the individual become, since in view of the Icelandic macro-paradigm, even if the subjects do not consent to their genetic scrutiny, the same result could be achieved by decoding the DNA of their family? Moreover, the *post mortem* problems that the 'Icelandic paradigm' is setting out are critical in this sense. Where there, if any, rights of the diseased, and if our answer to this question is a positive one, who could claim them and under which circumstances?

2 The unique character of genetic information and its connection to genetic identity and autonomy

Information in general bears a unique trend. It can be created by many and thus be co-shared; it can be transferred easily and in the era of globalisation almost rapidly and if controlled, can be used by indefinite subjects for a number of positive or even negative ends. The meaning of information is closely connected with the democratic theory, because of its enormous significance for the realisation of political freedom and participation as well as for public criticism. In this view, information is identified with transparency, public accountability and democratic control. The hugest problem that the acknowledgment of a modern right to control, access, use or process of information is facing, is the fact that it is difficult to define its subject, and thus to determine a relationship of 'ownership' as far as information is concerned. Literally, the current augmentation of data-banks, the vast expansion of cyberspace, the dynamic role that the mass media plays in the information era, render the understanding of a right to information as a traditional individual one more and more difficult. If information is to be controlled by its subject, its owner, if it is considered to be 'property' of an individual is a highly ambiguous matter nowadays. What are the reasons of such an ambiguity? A large part of what we can today describe as our personal information, including our genetic information – is shared with others. Certainly, in the course of our lives not all the information that we create is a part of our individual biography, many of it is constructed by our familial or intimate ties. To write for example in our autobiography that our husband was an alcoholic, in many ways lies in our freedom to reveal information

concerning our privacy, our intimate relationships. After all such facts in many ways have the ability to construct our identity, our personality.

More importantly the technological evolution defies the 'proprietary' character, this classic liberal bond, between the subject and its personal, intimate information, the ones we usually acknowledge legally as 'sensitive'. Truly, if cyberspace can be deemed as gigantic information database, who can question that it contains mainly personal information of, e.g., consumers. Moreover, who can doubt that from the moment that a little bit of information is out in the cyberspace, its subject has entirely lost its right to possess and control it use. The combination of information and technology has diminished the core characteristic that each right bears, the ability of power and control that entails for its subject. Additionally, it is extremely threatening for the privacy and especially the autonomy of the individual. If anyone can ultimately access or possess our personal information in what way can we still be defined as independent, self-driven and autonomous human beings?

Those are the reasons why the use of the term personal or sensitive 'data' instead of information in the legal literature on privacy is a two edged knife. It is not as simple to apply in legal science the fact that the current form of information is technologically constructed as to connect a legal norm with a factual reality. It also implies the acceptance of several implications such as, the free flow of information, their digital procession and their ability to disconnect from their subject or to be disclosed, etc. It entails an understanding of information as computer data, as neutral facts, with no origin, no subject, no control, data that can flow freely by the drive of their own or in the end by anyone's will. The understanding of information as data, is detaching the right to control one's personal information from its autonomy.

In order to define a right to genetic privacy, we must first define what kind of information can be considered to be genetic. The answer to that is a simple one. Our genetic information is what we call chromosomes. Each of us possesses a number of 23 chromosomes, which we inherit by half from our mother and father. The information that our chromosome contain are extremely comprehensive. Each chromosome carries a set of particular genes, which are responsible for the operation of every human cell. This genetic 'diary' is a set of combined coded information which we call DNA or genome. Why an individual has an interest in decoding his/her genome? In many cases, our DNA carries several 'defective' genes. In cases that those genes are inherited in two copies or even as a 'dominant' one, the individual might suffer by a number of diseases such as anaemia or cystic fibrosis. In this blueprint, an individual has a significant interest to be informed on his/her genetic material in order to exercise his/her right to marriage, family and especially reproduction as well as in order to plan his/her future life. Knowledge of genetic disorders enables the individual to better deal with or even avoid future illnesses. At the same thread, the evolution of medical research can enlighten even more this process, since in the future, it would be possible to detect a genetic component in a number of disorders that today we consider to be of psychological or social origins, such as alcoholism.

On the one hand, the capacity of genetic information to predict ones' medical future is what mainly differentiates it from any other medical information. Surely medical information in general can only identify but not predict a future illness or disorder, but mainly can provide with their causes and thus could affect their prevention or cure. Though in many cases, our genetic decoding can only give us probabilities and not certainties it can nevertheless provide the individual with the immense capacity to plan

his/her own future and guide his/her health and body choices, by understanding the inner depth of his/her physical identity. Given that the human body is considered to be the central mediator of autonomy and individual privacy, any decision and choice concerning its future health can be considered as private. In that sense, the deeper our knowledge of our genetic self becomes the further our autonomy is emancipated.

What distinguishes genetic information from any other medical information is that it represents a part of an individual's identity, meaning it represents a part of the subject's family heritage. We become who we are by connecting and communicating with the others, those we call intimates. Our familial genetic information can be represented as a form of such a bond, as a medium of communication. Thus, genetic information can foster a very intimate notion of identity, between an individual and his/her family. Each of us is characterised by his/her genetic links, his/her 'family resemblances'. Genetic ties and common genetic characteristics have the capacity to form a special kind of intimacy for a person which is a great part of our cultural heritage in modern western societies. It separates the individual from those with whom such a connection does not exist, while it is keeping together those with whom a genetic interconnection does in fact exist. The Paulik case clearly underlines this argument. Though the applicant, Paulik have believed for half a lifetime that he was the true father of his judicially acknowledged as such daughter, it was in the end the genetic truth that he was seeking. This truth had the ability to destroy any factual or legal tie that he had created in the meantime. Thus, our genetic identity is crucial for the family intimacy that we enjoy.

At this point, we can underline the following: what differentiates genetic from medical information is that is so much more than information. Genetic information bears a part of our personality, of our identity and autonomy. It cannot be deemed us neutral. On the contrary, one could say that it is extremely comprehensive. This was the central argument in *Marper versus UK* of the ECHR. The ECHR faced a case of retention of genetic information by the British police forces according to the Police and Criminal Evidence Act of 1984 (known as the PACE). The applicants, a minor S and an acquitted adult, Marper applied in the ECHR requesting protection under Article 8 of the Convention. The reason was that the two applicants' DNA material was retended although they were both found to be innocent or acquitted. The UK Government claimed the retention of their genetic data justified, for reasons of public interest and pubic safety, namely prevention of crime and terrorism.

In its decision the ECHR emphasised the chief characteristic of genetic data, distinguishing them from any other personal or even medical information. The ECHR noted the extremely comprehensive nature of DNA data, thus their capacity to unveil the subject's ethnic identity, family relations and hereditary diseases, central traits of a person's right to privacy and identity. Those characteristics forced the ECHR to underline that the retention of this information could severely affect the autonomy of the individual, since it entailed an indefinite loss of his/her genetic self-definition. What the ECHR should have added is that genetic information is not exactly neutral because they are so comprehensive and thus the entity (state or private) that gains control over it can literally control the individual itself, e.g., by discriminating against him/her.

At the end, the very characteristic that distinguishes genetic from medical or any other information is its ability to be identified with one specific individual. An individual's complete genome can link to his/her family but it is ultimately unique. It cannot be copied or cloned. Thus, from a moral point of view our genetic self is part of

what we can call authentic, or different in ourselves, it is part of what we can call identity, which means to differentiate us even from our family members. At the same time, this unique trend augments extremely the utility of genetic information for reasons of preserving the public safety. This trait is what clearly and without a doubt renders genetic information the character of sensitive, personal or private 'data'.