Preface

THE GENETIC SELF: AUTONOMY, IDENTITY, AND GENETIC PRIVACY IN THE ERA OF TECHNOLOGY

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 endeavors.

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 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 others but also the information that defines 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 we can consider them a “private matter” when our human genome contains information that we share with our parents, siblings, ancestors, and predecessors. In other words, does having a right to genetic privacy give the subject the autonomy to drive its genetic identification by his/her own will?
The Unique Character of Genetic Information and Its Connection to 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 globalization 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 realization 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 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; much 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 “proprietal” 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, for example, consumers? Moreover, who can doubt that from the moment that a little bit of information is out in cyberspace, its subject has entirely lost its right to possess and control its 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 form their subject or to be disclosed, etc. It entails an understanding of information such as computer data, 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 23 chromosomes, which we inherit by half from our mother and half from our father. The information that our chromosomes 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 that we call DNA or genome. Why would an individual have 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 a number of diseases, such as anemia 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 and not predict a future illness or disorder, and can provide 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 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 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 characterized 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 keeps together those with whom a genetic interconnection does in fact exist.

At this point, we can underline the following: what differentiates genetic from medical information is that it is so much more than information. Genetic information bears a part of our personality, our identity, and our autonomy. It cannot be deemed as neutral. On the contrary, one could say that it is extremely comprehensive.

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 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.”

**Privacy, Autonomy, and Identity of the Individual in the Era of Globalization**

The first section of the book, entitled “Privacy, Autonomy, and Identity of the Individual in the Era of Globalization,” examines the theoretical foundations of genetic privacy, namely the rights to privacy and dignity. Thus, in the first chapter of the book, “Privacy as a Right: History and International Recognition,” Despina Kiltidou presents a short but comprehensive conceptualization of the right to privacy. As she points out the rise of technology in the era of globalization is an opportunity for recapturing the right to privacy: Given the wide array of definitions of privacy, it can
be said that the term seeks its identity. Depending on time and space, this right has had various traits, beyond the obstacles of a strict definition. The aspects or features of the term are those that lead to the necessity of its international recognition and protection, especially in the present digital and technological environment, where its foundation is reconsidered and internationally protected in an effective way.

The major significance of the principles of substantial equality and human dignity for the fair and justified enjoyment of human rights is elaborated in the second chapter of the book, Christina Delliyianni-Dimitrakou. Exploring “Substantial Equality and Human Dignity,” she underlines that equality is a multi-dimensional concept. In the context of law, it is principally identified with formal legal equality comprising both numerical and proportional equality. Numerical equality grants all individuals the possibility to uphold the same rights and obligations before the law. Contrary, proportional equality imposes the same treatment of the alike and different treatment of the non-alike. Nevertheless, the second principle of proportional equality calling for unlike treatment of the unlike seems to be equally challenging. When implementing this principle, the emerging challenges stem from the widely accepted Western perception that identifies diversity with inequality and inferiority. This chapter explores these highly challenging issues attempting to enlighten the interpretation of the principle of equality in conjunction with the most cherished value of human dignity.

The second section of the book, entitled “Privacy, Sexual Autonomy, and Sexual Orientation: Threats and Limits,” explores the close connection between privacy, sexuality, and the individual’s most sensitive personal data, such as information regarding the health. The third chapter of the book by Christina M. Akrivopoulou and Theodora Roumpou, examines the subject of “Sexual Orientation, Female Genital Mutilation, and Health in Asylum Cases: International and ECHR Jurisprudence.” In this chapter, the two authors examine three categories of cases regarding asylum and refugee rights according to the Geneva Convention provisions (1951) and the European Convention of Human Rights (Art. 3): 1) cases where a fear of persecution to the country of origin is based on the applicant’s sexual orientation (homosexuality), 2) cases where the fear of persecution is connected with practices of female genital mutilation, and 3) cases regarding serious health problems of the asylum seeker. The jurisprudence of national supreme courts and EcHR on these subjects, especially regarding the interpretation of Art. 3 ECHR, which forbids torture, inhuman and degrading treatment, is analyzed. Although an international consensus exists today regarding the protection of asylum seekers on the basis of sexual diversity (homosexuality), in cases of female genital mutilation and health problems the national supreme courts and the EcHR are far more hesitant in acknowledging asylum rights and refugee status.
In the fourth chapter of the book, Athanassios Takis, analyzes the subject of “Refugee Claims Based on Persecution Due to Sexual Orientation before the Court of Justice of the European Union.” According to the author, the Court of Justice of the European Union recognized that under certain conditions, lesbians, gays, and bisexuals who face the fear of persecution in their country of origin may be granted international protection within the EU. In interpreting the relevant provisions of Directive 2004/83/EC on minimum standards for the qualification and status of third country nationals or stateless persons as refugees, the court affirmed that homosexuals constitute a social group unjustly targeted and persecuted. Once the conditions, which the court affirmed as necessary, are met, member states shall grant refugee status to third country homosexual applicants: a landmark judgment opening the gates of Fortress-Europe to homosexual asylum seekers but at the same time ensuring that these gates are not wide open. Balancing between the need to protect the fundamental rights of LGBT persons and to prevent a massive influx of applicants, the court followed a restrictive interpretation of the relevant provisions. This chapter presents the judgment and posits the partial incompatibility of the interpretation followed with the protection of fundamental rights.

In the fifth chapter of the book, Despina Tziola accounts “Sexual Orientation as a Human Right.” According to her view, worldwide, people are subject to persistent human rights violations because of their actual or perceived sexual orientation and gender identity. These human rights violations take many forms, from denials of the rights to life, freedom from torture, and security of the person, to discrimination in accessing economic, social, and cultural rights, such as health, housing, education, and the right to work, from non-recognition of personal and family relationships to pervasive interferences with personal dignity, suppression of diverse sexual identities, attempts to impose heterosexual norms, and pressure to remain silent and invisible. This chapter seeks the theoretical analysis of the subject based on a specific case study of the relevant UK Supreme Court jurisprudence.

In the sixth chapter of the book, Anastasia Pitsou analyses the subject of “Domination, Asylum and Sexual Orientation.” As she accounts, in the modern globalized society of control, denizens who exercise their right to seek asylum on ground pertaining to sexual orientation are forced to prove their homosexuality through various humiliating ways during the asylum-granting process. The author questions these procedures and poses a series of critical questions that need answers on the subject. Thus, do public authorities aim to reject the criminalization of sexual orientation? Furthermore, do they have the possibility to abolish the detention centres in the name of human dignity, human life and liberty, rights established by national, international, and European laws?
In the seventh chapter of the book, Despina Kiltidoy presents the “Case of Vallianatos and Others v. Greece: Another Step towards Realizing the Equal Protection of Same-Sex Relationships.” As the author analyzes, the case of Vallianatos and Others v. Greece concerns whether or not the “non-marital partnership,” designed solely for opposite-sex couples according to Greek law no. 3719/2008, should be extended also to same-sex couples. According to the judgment of the European Court of Human Rights the Greek Law violates rights protected under Article 14 (unjustified discrimination) taken in conjunction with Article 8 (right to private life) of the European Convention on Human Rights (ECHR). As the Court’s judgment underlined, the Greek law should be extended to same-sex couples as long as “civil unions” is not an alternative or flexible form of marriage. This case illustrates in the most characteristic manner the consequences that the state failure to protect sexual freedom has regarding social marginalization and discrimination in a national society.

The third section of the book concentrates in the matters of “Autonomy, the Abortion Controversy, and the Ethics of Sterilization,” and the repercussions for the rights to reproduction, the right to life, and the protection of human dignity. In this framework, the eighth chapter of the book by Fereniki Panagopoulou-Koutnatzi presents “Abortion: The Legal Voyage of the Unwanted Child.” As the author underlines, historically, traversing the ethical and deontological adventures of the unborn child with regard to abortion, the first known reference to the induced termination of a pregnancy is in a law of the Sumerians, circa 1800 BC. According to Sumerian law, if a man strikes a free-born (not a slave) woman causing her to lose her unborn child, he must pay ten shekels of silver as a fine for her loss, whereas if a man deliberately strikes the wife of a free-born citizen causing her to lose her unborn child, he must pay a fine of one-third of a mina of silver. This law contains no mention of voluntary termination of a pregnancy. Nowadays, one should underline that every human being at the very beginning of life and even before birth treads a long and adventurous road filled with moral dilemmas and legal repercussions. The fact that this refers to the life of every person-to-be is not under question in this treatise. Likewise, the authors assume that every human is the bearer of human dignity. These very crucial points and the relevant ethical dilemmas posed are analyzed in the chapter.

In the ninth chapter of the book, Christina M. Akrivopoulou and Maria N. Asproudi, analyze the issues of “Sterilization of Women: Legal and Ethical Dilemmas.” As the authors analyze, women, in many places of the world, frequently rely on access to sterilization procedures in order to control their fertility at will. However, this is not always the case. Often, women are forced to undergo permanent and irreversible sterilization, without been aware of it or without their informed consent. Despite the condemnation of such practices by the United Nations (UN),
cases of coerced sterilization are recorded all around the globe; in North and South America, Australia, Africa, Asia, and Europe, especially targeting women with mental disabilities, the poor or socially stigmatized, those perceived as “unworthy” of reproduction. Economic incentives, misinformation, and scare tactics are used as a means of enforcing sterilization to a person. Perpetrators are rarely held accountable for their actions and victims rarely find justice against this brutal violation of their rights. Forced and involuntary sterilization means grave violations of human rights and medical ethics, and may qualify as an act of torture, cruel and inhuman treatment. Such vile practices are significantly concealed because women affected the most come from marginalized parts of the population, hospitals and governments are unaware of such policies in order to protect patients’ rights efficiently and/or effectively, and medical professionals are not legally accountable for human rights violations and violations of medical ethics.

The tenth chapter of the book by Despina Tziola presents the subject of “Abortion and the Right to Life in the International Bibliography.” According to the author, the right to privacy can be found to rest on the provisions of habeas corpus, which first found official expression under Henry II in 11th century England, but has precedent in Anglo-Saxon law. Traditionally, American courts have located the right to privacy in the Fourth Amendment, Ninth Amendment, Fourteenth Amendment, as well as the penumbral of the Bill of Rights. The landmark decision, Roe v Wade relied on the 14th Amendment, which guarantees that federal rights shall be applied equally to all persons born in the United States. However, society’s view on abortion is not clear, as it depends on many different factors and reasons. Abortion has been a controversial subject in many societies through history because of the moral, ethical, practical, and political power issues that surround it. It has been banned frequently and otherwise limited by law.

However, abortions continue to be common in many areas where they are illegal. Every year, hundreds of UN negotiations examine questions related to virtually every conceivable social issue. As a result of these negotiations—the most prominent of which are the periodic five-, ten-, and fifteen-year reviews of major UN conferences on the environment, population, women’s rights, and human settlements—various reports, platforms, agendas, and declarations are issued, updated, and expanded. Not long ago, these “soft law” documents were considered little more than helpful—or, perhaps, even irrelevant—suggestions. Today, they are more than mere words. “Soft” international law has also been found determinative in discerning the content of the Fourteenth Amendment. Although, the way a country deals with abortion is highly symbolic of women’s status and how it treats women generally. Those who believe there are more important things to put right than unsafe abortion are, in effect, making a statement that women’s health and lives do not count.
In the eleventh chapter of the book, Anastasia Pitsou presents the European Court of Human Rights case law regarding abortions in Ireland. She offers a critical account of “The Conservatism of the European Court of Humans Rights Regarding Abortions on Demand.” As she points out in the relevant case law, the European Court of Human Rights (ECtHR) missed the opportunity to recognize the right to abortion under specific criteria that are harmonized with the right to life and the right to privacy. It obviously remains a triumph of nationalism and of religious power over human dignity.

In the fourth section of the book, entitled “Genetic Privacy, Biometrics, and Dignity,” the impact of biometric technology on the rights of genetic privacy and dignity is examined. In the twelfth chapter of the book, Elsa Supiot and Margo Bernelin analyze the issue of “Genetic Privacy: A European Design or Default?” In their chapter, the two authors analyze the European Union framing of the protection of genetic privacy in the context of the European Commission’s 2012 proposal to amend the 95/46/EC Data Protection Directive. This market-driven proposal, fitting a wider European movement with regard to heath-related legal framework, takes into account the challenges to privacy protection brought by rapid technological development. Although the proposal is an attempt to clarify the 1995 Data Protection Directive, including the question of genetic data, it also creates some controversial grey areas, especially concerning the extensive regulatory role to be played by the European Commission. With regard to genetic privacy, this chapter takes the opportunity to develop on this paradox, and gives an analysis of the European design on the matter.

The thirteenth chapter of the book, authored by Evanthia Chatziliiasi and Athena Bourka, is entitled “Remarks and Considerations on the CJEU Decision on Biometric Passports.” According to the authors, biometric passports, namely passports including a storage medium that contains the facial image and two fingerprints of their owner, became mandatory when Regulation (EC) 2252/2004 entered into force. In the case C-291/12, the Court of Justice of the European Union was asked to examine whether biometric passports constitute a possible infringement of the fundamental right to the protection of personal data. This chapter aims at analyzing the aforementioned Judgment of the CJEU, focusing in particular on the application of the proportionality principle. The authors attempt to formulate some additional remarks and considerations on the critical matters of that case, and to this end, they especially focus on the processing of multiple biometric elements, the existence of alternative and less intrusive means, as well as the security of the biometric passports.

In the fourteenth chapter of the book “Hunting HIV-Positive Women in Greece as Parasites,” Anastasia Pitsou examines a specific case of violation of privacy and
dignity of HIV/AIDS positive women prostitutes. The author accounts the case of HIV-positive prostitutes that have been imprisoned in Greece while their personal data regarding their health have been published in newspapers and the social media. The author in this chapter is aiming at drawing a balance between the right of the citizens to be informed on matters of public health and the stigmatization of the HIV/AIDS-positive women prostitutes.

In the fifteenth chapter of the book, “Privacy Nudges: An Introduction,” Barbara Sandfuchs finds that to fight the risks caused by excessive self-disclosure, especially regarding sensitive data such as genetic ones, it might be desirable to prevent certain disclosures. When doing so, regulators traditionally compel protection, for example by prohibiting the collection and/or use of genetic data even if citizens would like to share these data. This chapter provides an introduction into an alternative approach which has recently received increased scholarly attention: privacy protection by the use of nudges. Such nudges may in the future will provide an alternative to compelled protection of genetic data or complement the traditional approach. This chapter first describes behavioral psychology’s findings that citizens sometimes act irrational. This statement is consequently explained with the insights that these irrationalities are often predictable. Thus, a solution might be to correct them by the use of nudges.

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