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The Implementation of the European Directive 95/46/EC in Greece and Medical/Genetic Data

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1. The European Directive and L. 2472/1997

Medical and especially genetic data have become a number one legislative importance in many European countries and in the Unites States. This new legal domain is 'fashionable', à la mode; at least in Greece, new faculty positions open in the Law Schools with data protection as the main theme of the courses they relate to, and a number of articles on data protection in the major Greek law reviews has been published. People fear more than ever that their personal data may flow from one computer to another and that what their personal private doctor knows about them may very well now be in the hands of an insurance company, a security fund-wherever.

But it is not true, strictly speaking, that the question of data protection first arose in Greece after the European Directive 95/46/EC, or that Greece provided no legal defense for impermissible data violations before the directive. Quite the contrary: Greece had ratified the Council of Europe Convention of 1981 (28.1.1981) for the Protection of Individuals with Regard to Automatic Processing of Personal Data (L. 2068/1992-it is true, though, that Greece did not, at the time, proceed with specific rules on the matter). The general clause of the protection of personality, Art. 57 of the Civil Code, an article notably absent in many European Civil Codes, could serve as grounds of liability for any impermissible processing of personal data. All the indications from our jurisprudence are clear, that the Greek courts were ready to interpret the clause for the protection of personality as a proper foundation of a cause of action aiming at the prescription of the illegal processing of personal data and, most importantly, at an award for damages for moral harm (non-pecuniary losses) independent from any physical or generally, tangible, injury. Art. 57CC has been applied widely enough as to permit such a statement and this fundamental provision has 'saved' us from a number of,

impossible to foresee at the time of the Civil Code's drafting, cases. Personal data could be one of them. Apart from this, a series of draft bills were introduced in the Greek Parliament for discussion and voting (in 1989, in 1990, in 1991 and in 1992), none of which managed to reach a meaningful discussion, let alone a decent vote. A relevant bill proposal in 1992 was rejected. A last draft bill in 1994 also followed its predecessors' fortune.

Upon this background, it came as no surprise that Greece played a major role in the formation of the European Directive 95/46/EC (Greece was also the Head of the European Commission at the time). The Directive is a detailed and very fundamental instrument, no doubt, but it called for specific legislation for its' true implementation. This specific statute for Greece was L. 2472/1997, 'On the Processing of Personal Data'. For the first time, among other novelties, the victim of an illegal processing of personal data was offered a remedy, damages for both economic and non-economic losses.

L. 2472/97 and medical data. Medical (and of course, genetic) data belong in the statute's list of 'sensitive' data (Art. 7, sec. 1). The European Directive listed medical data in 'special categories of data' (Art. 8, sec. 1). The Greek legislator preferred the word 'sensitive' as an indicator of something more than 'special'. Medical data, therefore, come as similar in nature with data revealing ethnic or racial origin, data on sex life, on one's criminal record, political and religious opinions etc. The processing of all sensitive data, medical data too, is only allowed under the following conditions (Art. 7 sec. 2): a. The data subject has given explicit written consent to the processing of those data (consent is, though, invalid, if given against the principles of good morals or if consent is prohibited by law) b. Processing is necessary to safeguard vital interests of a data subject legally or physically incompetent to give a valid consent c. Processing is necessary for the data subject's defense in a court of law d. Processing is necessary to protect the data subject's interests in health and it is carried out by a health care provider under the obligation of confidence e. Processing is necessary to further national security interests and needs of the state's criminal or correctional policies and f. Processing is related to personal data of public persons connected to the exercise of their public duties and this processing is a part of the exercise of a journalist's duties. Consent of the person related to the medical data is legal only if it is clear and explicit, and only if it was given after this person has been fully informed on the purpose of processing, the nature of data to be given, the recipients or categories of recipients of the data and the filing system controller. In any case, this controller is obliged to file for a license to process sensitive data to the Greek Authority of Data Protection, which was also instituted by the statute.

Sanctions. The sanctions for the impermissible processing of medical (and

other) data are diverse: civil sanctions, penal sanctions and administrative sanctions. The civil sanctions include a minimum of damages payable to the victim of the illegal processing of data for non-economic loss (an impressive step for a State traditionally hostile to any damages for moral harm). These damages, as a satisfaction for moral harm, may never fall below the limit of € 5.869, unless the offense was negligent, or the plaintiff claimed a lesser amount. This monetary satisfaction is awarded independently of any other compensation for economic loss. The procedure implemented to resolve the relevant disputes is the quick summary procedure under Art. 664, 676 CCivPr. The State may also bear civil liability, for acts or omissions of its organs, under the general provisions of IntrCC 105-106. Penal sanctions are threatened for two classes of offenses: for certain acts or omissions as the breach of the obligation to notify of the existence of a file, the function of a file with sensitive data without a license etc, and also, for the non-execution of a decision issued by the Authority of Personal Data Protection.

Criminal sanctions start from a jailing penalty of up to three years and reache the penalty of up to ten years incarceration, for anyone who breached certain provisions of the statute with the purpose of acquiring or giving to a third party an illegal pecuniary benefit to harm another one. This grave penalty is also coupled with a possible pecuniary penalty from € 5.869 up to € 29.347.

Administrative sanctions. The Authority for the Protection of Personal Data, has the power to impose grave administrative sanctions upon any file controllers and their agents, starting from a simple warning setting a time limit for compliance, a fine from 880Euro up to 14,735Euro, a temporary revocation of license to operate and also, an order to destroy all files or to cease any processing and extinguish all relevant data.

Authority for the Protection of Personal Data specifically. The Authority is responsible for the control of all legal or natural persons and entities that possess and use files of personal data. The Authority supervises the implementation of L. 2472/97 in Greece, the formation and the operation of all personal data files. In particular, the selection and the processing of data by a certain company has to be linked to the objectives of the company; also, the processing of those data is allowed only as long as it is necessary and according to a legitimate purpose. The Authority of Personal Data Protection is an independent administrative agency and it enjoys independent funding and Secretariat. The actions by this independent Authority are not, in principle, subject to any control by the executive power. The Authority consists of five members (a Supreme Court justice as head, a law professor etc) who may change every four years (half of them change every two years). Only the head of the Authority is appointed by the Ministers Council. A

number of legal safeguards restricting the eligibility for membership in the Authority secure the Authority's independence. This Authority has extensive competencies. It may contribute in the drafting of codes of ethics by associations and organizations, may conduct administrative controls, may impose sanctions, may issue legislative texts, may announce at the Parliament the breaches of the statute, may submit annually a Report at the President of the Parliament on the Authority's actions and the condition of data protection in Greece. The Head of the Authority may also act immediately, whenever needed, and edit a temporary order restricting or prescribing the processing of certain data or the function of a file. This order is in effect until the Authority reaches a final decision in plenary session. The Authority has its own records and Art. 4 regulates access to these records. All public authorities are obliged to offer any contribution and help necessary for the Authority's function.

2. Genetic data and national legislation

Genetic data are seen today as a special class of medical data, in need for also special protection. A large body of legal theorists sustain that genetic information is 'unique' and legislators have followed this view (the United States, for example, have issued, among others, the federal Genetic Privacy Act drafted in 1995). A series of States afterwards followed with a great number of bills on genetic privacy. Writers discuss a 'genetic privacy right', and even more than that 'personal data'; genetic data are today more than ever in the center of attention.

a. The 2001 constitutional revision and genetic data

In Greece, the 2001 revision of the Constitution offered the chance for the inclusion of a specific mention of genetic data. It is true that Greece had ratified the (Oviedo, 4.IV.1997) Convention of the Council of Europe on human rights and biomedicine (L. 2619/1998). The statute prescribed, as an internal law, any discrimination against a person because of her genetic inherited material and allowed a medical examination searching for genetic information only for medical reasons or for research related to medical reasons, and always under the necessary genetic counseling (Art. 11 and 12). The truth is, though, that the ratification of the convention was a general instrument, a lex imperfecta, as it did not contain any sanctions for the breach of the above rules of law. The articles on genetic data which were added to the Constitution in 2001, as part of the work of the Z Revisionary Greek Parliament, were also general. A section 5 was added to Art. 5 of the

Constitution, Art. 5 being the major provision on the protection of the free development of personality and human freedom[1]. This (new) section reads: 'everyone has the right to the protection of her health and her genetic identity. A statute shall provide the necessary protection of a person against biomedical interventions.' The interpretation of the phrase 'protection of genetic identity' necessarily involves the protection of genetic personal data. For sure, when someone 'steals' my genetic data and forwards them to an insurance company without my consent and even, without my knowledge, then my (new) constitutional right to the protection of my genetic identity has been violated (even if the central purpose of the section may have been to protect against unconsented and illegal biomedical interventions, also involving genetic engineering etc). Thus framed, the section seems like the embodiment of the right to genetic privacy-a new, defensive right to genetic privacy ('do not breach my genetic privacy'), as part of the old, defensive form of the right to freedom[2] ('do not prosecute me, arrest me, jail me, restrict me unlawfully').

The natural question follows, why was not this new 'genetic privacy right' added as a section to our general, classic, old, right to privacy, Art. 9 ('..private and family life of a person is inviolable...'etc). Art. 9 was indeed not left 'untouched' by the 2001 constitutional revision. Quite the opposite is true: a new article 9A was added right after Art. 9, notably, a new article of the protection of personal data, which reads: 'Everyone has the right to the protection of the collection, processing and use, especially by electronic means, of personal data, as the law provides...'[3]. Art. 9A, therefore, embodies the (new) constitutional right to 'personal data privacy'. There is no doubt that this right to personal data privacy is framed as part of the general right to privacy, the king of the defensive rights, the plain 'right to be let alone', the shield but never the sword. The combination of the new sec. 5 of Art. 5 and the new Art. 9A leads to the safe conclusion that in Greece, today, there is a constitutional right to genetic privacy, including the right to the protection of personal genetic data and that this right belongs to the defensive rights, in fact it is a sub-category of the general right to privacy. The speaker for the majority in the final meeting where the consitutionary revision was voted, Evaggelos Venizelos[4], was absolutely explicit on this point[5], titling the first of the five[6] principles, on which the systematic revisionary constitutional policy was based, as 'the principle of the security of the person'. Under this principle come, he noted, among others, all sections on biomedical experimentation and personal data. This 'fourth generation of constitutional rights' consists a new modern 'breastplate' in favor of the citizens[7]. What Venizelos termed 'breastplate' is, very conveniently, the shield I mentioned above. Nowhere in the text of this speech do we find any other possible meaning, or

interpretation, of the right to the protection of personal, and genetic data-say, for example, a positive, also, and not only defensive, aspect of this right.

A last note: the constitutional revision of 2001 also added a very important line in the Constitution. All individual and human rights listed in the first 25 articles of the Constitution are deemed applicable not only in the public law relations between a citizen and the State (old conception of individual rights protection), but also in any other private law relation between private parties where they may be applied (Art. 25). In short, for the purposes of this article, what the State cannot 'do' with a person's medical or genetic data, no private party may 'do' as well. Thus, Greece abolished the need for the use of a whole theory (theory of the applicability of human rights provisions in private law relations-theory of 'Drittwirkung', that used to fill the gaps of the non-existent constitutional protection for violation of human rights by private persons – it is, indeed, a pity that so much has been written on the subject the last thirty years. The possible implications of this major change is that organizations like insurance companies, large employers, banks etc etc will have to adhere to the protection of the genetic privacy of people they deal with exactly as if they were the State-and small employers too: in fact, absolutely everybody. And what they violate, if they will, while interfering with people's personal sensitive or not data, has now the highest possible legal protection: the constitutional one. Probably, we lawyers have just to watch a flow of lawsuits long awaited but legally impossible.

b. Statutes and other sources of law on genetic data

i DNA analysis and crime

As parts of a constitutional text, the new constitutional provisions do not include sanctions for their violations; this is left to the parliamentary lawmaker. The parliamentary lawmaker was, in her turn, not slow in drafting at least one statutory provision related to the protection of genetic data. In the course of the revision of some articles of the Code of Criminal Procedure, and after heated parliamentary and other debates throughout the country, a new article 200A was added to the Code of Criminal Procedure, on the conditions of a legal DNA analysis. Section 1 reads: 'When there exist serious indications that a person has committed a felony with the use of violence, or a crime against sexual freedom, or acts of constitution or participation to organization under par. 1 Art. 187 CrC, the competent judicial council may order the analysis of the DNA in order to ascertain the identity of the actor of this crime. The analysis is restricted to the data absolutely necessary to the above confirmation and is conducted in a state or university laboratory. A

defendant in a criminal action may also ask a DNA analysis for her defense.' Sec. 2 reads: 'If the DNA analysis is positive, the finding is notified to the person whole genetic material was analyzed. The person is entitled to ask that the analysis be repeated....If the analysis is negative, the genetic material and the genetic prints are immediately destroyed. If the analysis is positive, the genetic material is destroyed but the genetic prints remain only for the needs of the criminal trial in the case file.' We should note that the Opinion n. 15/2001, issued by the Authority for the Protection of Personal Data (after a special question by the Minister of Justice Pr. Michael Stathopoulos in February 2001, in view of the new statutory provisions) did recognize the severity of the matter, but expressed several concerns on the DNA analysis for the investigation of crime[8] and allowed it only for specific crimes. In the crime list of the Opinion, the crimes related to terrorism were not explicitly reported. In fact, terrorism appears nowhere in the Opinion.

Looking at the statute from a certain distance, what could seem as the execution of an order by the constitutional lawmaker to protect genetic data, became instead a license for DNA analysis (under certain conditions) which was illegal before the revision of the Code of Criminal Procedure. It looked like the promised 'breastplate', the shield, suffered an immediate attack that made it feebler than ever before. The possibility of an order for DNA analysis under the sole condition of 'serious indications that....' (see above paragraph) was met with severe criticism by a number of very different forums, starting with the Bars of cities all over Greece, major law personalities, various organizations, the Press and others. An indication, even a serious one, is always just an indication and the article contains no definition of a 'serious indication'. Is the mere presence of a suspected person near the site of a committed crime coupled with a criminal record enough to justify a 'serious indication' of guilt? Who in fact will be the subject, and therefore the judge, of a 'serious indication'? What are going to be the consequences of a person's refusal to submit to such an analysis? The article does not contain an answer. Fears of abuse of Art. 200ACCrPr by the police and the judiciary were widely expressed. The truth is that terrorism has become a major concern for every state in Europe, the US and of course others, and it is, in fact, true that terrorism hides behind Art. 200ACCrPr. It remains to be seen whether the article is substantively compatible with the remaining of our national legislation on personality interventions and whether it will be abused instead of used.

ii Statutes on medical confidentiality

Medical confidentiality of course is a very old legal rule. There are no special

statutory rules on the protection of medical 'data', as they fall within the ambit of the rules on medical professional secrecy. The breach of the principle of medical confidentiality is firstly a criminal offense. Under Art. 371CrC, this offense is punished with a pecuniary penalty and/or up to one year incarceration[9]. A sole justification of the offense is in sec. 3 (the act remains unpunished if the responsible person was executing her duty or was preserving a lawful or other justified material interest of the State of another person, which could not be preserved differently). The Code of Ethics of the medical profession protects medical confidentiality in Art, 15 and Art. 18 (R.D. 25.5/6-7.1955, 'On the Regulation of Medical Ethics'). The Code of the Exercise of the Medical Profession (C.L. 1565/1939, Art. 23) also contains essentially the same provisions. The crime of the breach of medical confidentiality is punishable only when committed with intention. The question whether the patient's consent may legalize the breach has not been clearly answered[10].

Medical data that have to be reported under special statutes include: the birth of a child (L. 344/1976, Art. 20-30), the death of a person (L. 344/1997 and Art. 442CrC) and certain diseases (like, for example, smallpox and, of course AIDS) that may be transmitted widely in the public must be reported to the public authorities[11]. Physicians also have the obligation to inform the authorities when they suspect an incident as indicative of a crime or a crime attempt (for example, when they suspect child abuse, a change of sex or plastic surgery of a person's face to cover crimes etc), otherwise they may face criminal charges (232CrC).

The statutes may well protect confidentiality, but they contain vacuums and, moreover, everyday practice shows many 'gray' areas. Physicians acting as experts in evaluation of a candidate for insurance report their findings to the insurance company, thereby abolishing the obligation to keep medical data secret. The insurance companies are deemed to have an interest in knowing medical data about patients who claim an insurance coverage. It seems that the physicians have a contractual obligation to inform the insurance company of their findings, even if they are medical data originally privileged. Various insurance funds demand to learn in writing an exact diagnosis before they start paying for medicines and cover all related expenses. The legality of these practices is dubious, a result that becomes crystal clear when the disease involved carries with it a social stigma (p.e. a mental illness). A solution could be the report of the illnesses under a specific number and not their name[12]. The Authority of Personal Data Protection will probably improve the situation soon.

iii The ADP Opinion of medical/genetic data and the workplace

As a guideline until now, the Authority[13] has issued an Opinion on the transmission of data and the workplace. The Opinion is applicable as a guideline in both the private and public sector. Any collection of medical data in order to evaluate a candidate for work have to be done only by the candidate herself. The purpose of the transmission of information is strictly to judge whether a particular person is suitable for a job demanding special conditions of health, as in nurseries, restaurants, hotels, or when the candidate wishes to work as a pilot etc. The collection of information is also legal when the purpose is to offer to the claimant a certain benefit that is health-related. On genetic data, it is as a rule forbidden to collect or ask for genetic data. The Opinion supports that it is never legal to involve genetic data and a person's work, as this would violate the principle of proportionality (between a measure and the harm it may cause) and also, the constitutional principle (Art. 2C) of the dignity of people. Any consent given is automatically null and void. The only case where an analysis of genetic data may be valid in labor situations is when the health of the subject is promoted by the analysis, when no other solution exists, after informing the subject and obtaining a legal consent to the genetic analysis and after a special license to be given before the examination takes place by the Authority for the Protection of Personal Data.

3. Some last remarks

Is a patient's privacy today well protected in Greece? The new law on personal data, L. 2472/1997, was not designed to protect patients, but all citizens-that medical and genetic data belong to the 'sensitive' data category, and are, therefore, afforded a special status, is a step forward. The new constitutional article dictating that everyone's genetic identity shall be protected (Art. 5 sec. 5) certainly shows the concern of a constitutional lawmaker about possible violations of people's security in their bodies and their genetic material. The institution of the Authority for the Protection of Personal Data, its power to condemn file controllers to heavy monetary penalties, and its work so far shows that Greece is moving towards the correct direction. The statute's provision for criminal liability is an additional safeguard. Statutes on medical confidentialty exist and there are also relevant rules in ethics regulations.

On the other side, reality is not so happy. At the present, a mentally ill person who needs medication to be paid through an insurance fund has no other option but to report the illness to this third party. Indeed, this is true for

any patient whatsoever, because an individual may wish that any disease she may have not be reported to a third party. That the patient who declines to send the physician's diagnosis to the fund will not be indemnified is a sufficient threat to make people follow the standard procedure. This is a blatant breach of privacy people have learned not only to accept, but quite possibly, to consider natural. And this is the most dangerous point, when citizens do not even notice that they have been crucially wronged.

The above is correct as a matter of law. On the side of ethics, all hospitals and clinics should adopt, as soon as possible, codes of ethics determining who, among the whole staff, shall have the access to patients' files, for what purpose and up to which limits. We expect the Authority for the Protection of Personal Data to act towards this direction immediately and the information we have today is that this will happen.

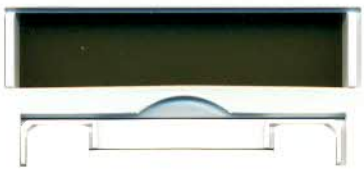
The message for the constitutional lawmaker is not happy as well. Many Greek writers have pointed out that the right to one's personal data should not be treated as a classic defensive right, part of the right to privacy. It is not wrong to classify it as a subsection of the right to privacy, initially; what is wrong is to exhaust the protection of this right's status negativus. The advances of technology offer a limitless possibility of a data combination and the creation of a profile of data on one's personality. In this case, these informative profiles are created in the citizen's ignorance. What is at stake is not only how we can protect a sphere of private life which has become increasingly difficult to define, but in general, the freedom to develop one's personality as one wishes and the possibility of communication in a society that makes decisions on the free dissemination and processing of information. The defensive side of the right to data has to be coupled by the aggressive side: the right of a citizen to determine actively, legally, who and when shall have access to her personal data[14]. As with a series of other rights currently thought of as founded on the right to privacy (right to medical information, right to abortion, right to euthanasia etc) their treatment as defensive rights has lead to conceptual inconsistencies and, most importantly, to substantial miscarriages of justice[15]. For defensive rights, by their nature, have to 'wait' for an attack, before they may be used to guard off the 'enemy', after which 'defense' they cease every function. As defensive they cannot afford the citizen, or the patient, the luxury of demanding by others positive acts of their respect. And the time that people, and of course patients, who need even stronger protection, due to their initially already feeble position, only needed shields against attacks has past.

The constitutional lawmaker, however, although warned, declined to construct such a right. And while it is true that in other European countries, the same route has been followed (not though, for Germany, for example), this

is a solution very difficult to justify solely on comparative law arguments. We can do no more than continue to press for the recognition of the right to informative privacy as described above.

Notes

1. The position of the new section in Art. 5 is crucial to its subsequent interpretation. Sec. 1 of Art. 5 deals with the right to the free development of one's personality (a positive right), sec. 2 protects everyone in the Greek State in terms of health, honor, freedom prescribing any discrimination due to nationality, race, language and religious or political beliefs, sec. 3 is the classic defensive right of freedom, prescribing any prosecution, arrest, incarceration or any other restriction, unless as the law provides, a new sec. 4 deals with individual administrative measures restricting a person's movement to and from Greece and the new sec. 5 reads as in the text above. That an article of the protection strictly of health and genetic identity, modeled as a classic social right (everyone has a right to the protection of her health etc) finds itself in the list of the protection of individual freedom and most importantly, after the defensive form of the right to freedom (after sections 3 and 4, that is) calls for a certain interpretation. What the reader understands is that, when the right to health is violated, or when a person's health is not protected, then a person's right to freedom has been violated. Also, the reader will assume that, when a person's genetic identity is not protected, then the person's freedom has been restricted. The last sentence ('a statute provides for the protection of a person against biomedical interventions') leads to the conclusion that the right to the protection of health and especially, our genetic identity is in essence a defensive right to freedom from (illegal) interventions and interferences with our health and genetic identities. A right, that is, that shields us from positive and aggressive actions against our health and genetic identities. This systematic interpretation of the new section comes as natural and does not seem wrong or problematic. When it comes, though, to the wrongful interference and meddling with genetic data, the question of which right was violated and what was the nature of that right immediately demands a wholly different analysis. And whether the protection of health and genetic identity through a defensive right to freedom only (and not though, also, a positive right calling for positive measures of protection) is complete is another matter altogether.
2. The positive form of the right to freedom is sec. 1 of Art. 5, free development of personality.
3. A section of the Authority for the Protection of Personal Data ends Art. 9A.
4. Minister of Culture today and Professor of Constitutional Law.
5. Venizelos E., The legal and political meaning of the revision of the Constitution, speech in the Greek Parliament, speaker for the majority, 6.4.2001.
6. The other principles were: the principle of the participation of the citizen (new provisions on decentralization, civil servants, independence of judicial branches etc), the principle of the transparency in the function of the State and the relations between the economy and the State (provisions on mass media, the funding of the political parties etc), the principle of the consent of all political forces (new electoral system etc) and the principle of the European perspective of the country.
7. Id.
8. '...DNA analysis is projected lately as the panacea for the resolution of severe crimes..', Opinion, under sec. 5.
9. This is an article relating to a series of professionals, and not only physicians (members of the clergy, pharmacists, notaries, attorneys, nurses, and others).



10. See Koutselinis, Fundamental Principles of Bioethics, Medical Ethics and Medical Liability, 1999, p. 154.
11. Id., p. 115.
12. The truth is that an expert may very well identify some mental diseases through prescribed medicine in any case. This transparency stresses the need for privacy and certain safeguards even more. A mentally ill patient who needs medication paid by an insurance fund has in the present no other means but reporting the disease and the medication to this third party.
13. The website of the Greek Authority for the Protection of Personal Data is: www.dpa.gr. All Opinions are included therein.
14. See Donos P., The Constitutional Safeguard of the Citizen's Right to Protection from the Processing of her Personal Data and the Relevant Independent Authority, in Revision of the Constitution and Modernization of Institutions, Ed. Papadimitriou G., 2000, p. 111.
15. See on the theoretical aspects Mitrou, Privacy: The Reluctant and Uncertain Course of the Protection of Personal Data, The C, Scientific Conventions, Twenty Years of the Constitution 1975, 1998, p. 33, 37. See also, on the practical results, Canellopoulou-Bottis, The Problem of Founding the Right to Medical Information and Abortion on the Right to Privacy, notes on L. 2619/1998, KritE 2000/1, p. 180.