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Habeas data and patient self-determination

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Abstract

In the digital era, the rising of new rights that redefine the very integrity of the person and legitimize their protection, especially in the field of health, calls for a reflection on the transition from habeas corpus to habeas data. The ancient habeas corpus, personal freedom understood as physical freedom, is now also a habeas data, in terms of digital freedom and the protection of personal information about the physical body. In this passage, the traditional legal culture clashes with the emergence of an information and knowledge society in which full and objective correspondence with constitutional concepts and rules is lacking. This is also happening in the health sector. Information in the medical field is an essential element, indispensable to be able to prepare the right treatment. The physician can collect, organize, and interpret patient data for the most correct diagnosis possible. Medical science, therefore, is information "from" the patient and "about" the patient, which is objectified through the computerised aggregation of the data of everyone undergoing medical treatment. Medical information becomes health data when it is processed, transforming it into a documental element of a digital nature. This article aims to give a theoretical contextualization of the concepts of habeas data, self-determination in the digital field and the issues related to informed consent and access to personal data.

Keywords: Habeas data, self-determination, information, access, informed consent

1. What is "habeas data"?

The cognitive analysis that moves from the right of habeas corpus of European legal culture to the constitutional guarantee of habeas data is one of the main innovations in the modern constitutions of Latin America, Africa and the former "satellite countries" of Eastern Europe (Acuña 2002). Although most of these rights were conceived and elaborated by European doctrine during the first half of the twentieth century, it is the "young" Constitutions established after the 1970s which represent a concrete example of legal production and guarantees which give importance to new rights such as: the right to data protection (as protection of the various rights of the individual which may be infringed by the laws of the Member States); the right to protection of personal data (as the power of the individual to obtain from public authorities, the defence of those rights violated or threatened by access, transmission, transfer, etc. . of one's own personal data); freedom of information (understood as the right to the informative self-determination of the person, i. e. the right to determine the when, how and quantum of a personal information subject to communication to third parties); freedom of information (as the personal guarantee to know and access personal information existing in databases, in electronic format, to control their content and therefore to be able to modify them in case of inaccuracy or undue storage or processing, and finally to decide on their circulation or transmission). Another new element foreseen in all modern constitutions of Latin American countries concerns the establishment of the constitutional guarantee of habeas data, according to which people have the right to claim that the image (even digital) that others have of them corresponds to the exact reality (Preite 2007). The

term habeas data has been proposed, therefore, to indicate a new and specific instrument of protection, symmetrical with respect to the pre-existing and traditional habeas corpus, precisely to protect the privacy and liberty of the citizen against computer abuse, a need that arises and develops with the new forms of interpersonal and also inter-institutional communication typical of the digital era (development of computer and information technologies, interconnection of world networks, development of new digital communication channels, telematic management and transmission of data). An important example in this area is the Constitution of Brazil, which contains declarations and principles not found in European Constitutions. In 1988 the Constituent provided for this new instrument of the citizen's freedom suitable for its safeguard against information technology even if, until the issuance of specific norms on the procedure of habeas data, the Brazilian jurisprudential practice continued to apply the procedure of "amparo", which takes the name of "mandado de segurança", a kind of special "amparo" of preventive type (to avoid the collection of information, mismanagement or treatment of the same) or of repressive or corrective type (to annul, rectify information or personal data that is false, incorrect or incomplete) with priority over all judicial acts except for the amparo itself and the habeas corpus (Acuña 2002). Unlike the Constitution of Brazil, in the Constitution of Paraguay the institution of habeas data has a much broader content as it includes access to information relating also to personal property, moreover it allows not only the rectification of data, but also their destruction if they are wrong or simply compromise other fundamental rights in an illegitimate manner. Every person has the right to know how the information will be used and what the purpose is. These are the substantial differences from the Brazilian Constitution, differences that offer more guarantees and broaden the object of protection of this right. In the State of Peru, the insertion of the institution of habeas data in the Constitution has taken place in a "contractual" form insofar as the right to the rectification of personal data is not contemplated, but the rights against the violation of which recourse is permitted are specifically regulated by reference to articles of the Constitution. In Ecuador, the 1997 Constitution, after the section on habeas corpus rights, includes a section on habeas data. It is not by chance that the paragraph is placed in this section of the Constitution entitled "Guarantees of Rights". As for the Constitution of Brazil, here, the insertion of the institution of habeas data was intended for the protection of particular "levels" of freedom of the citizen regarding personal information from other inmates. In addition to the possibility of correction and rectification of the data, their cancellation is also permitted. Other Latin American States, in addition to the traditional habeas corpus, included in the Constitutions for the protection of freedoms, contemplate the right of access to information in some articles of the relevant charters, without further specification and without indicating the possibility of making a habeas data appeal, as is the case in the Constitution of Guatemala in which there is a specific article regulating access to State archives and records.

2. Digital self-determination in health institution

The principle of digital self-determination, affirming itself as a social phenomenon through the passage from a process of "affirmation" of the person to an effort of "denial of the exclusivity of others", assumes the meaning of an unsuccessful attempt to preserve what remains most dear: «the fetish of a free will» (Frosini 1991). Being unable to assert himself, the subject can only limit external influences, not eliminating them, but reducing their scope and consistency to an acceptable level of tolerability. The development of information and communication technologies (ICT) and their use in all fields of human activity has represented a significant turning point in the application and interaction of computer knowledge. For example, the strategic use of these technologies in the health sector has led to the implementation of an eHealth model that is embodied in the combination of information technology, medicine, administrative science, and law, with the aim of affirming the centrality of the patient and his care, but which is counterbalanced by the problem of the use of his data. The data of each in-

dividual undergoing health treatment thus becomes an object of use and study (Preite 2014). Also, in the field of health, therefore, there is the passage from habeas corpus to habeas data, that is, from the protection of personal freedom in a merely physical sense to the protection from "any other restriction of personal freedom". Information in medicine is an essential element, indispensable to be able to prepare the right treatment. It is up to the doctor to collect, organise and interpret patient data for the most accurate diagnosis possible. Medicine, therefore, is information from the patient and the patient, which is objectified by the computerized aggregation of the data of each individual subject to medical care. Medical information becomes health data when it is observed to be humanly handled and processed, which transforms it into a document, even in electronic form, and creates a burden on the healthcare provider to protect new rights, including the right to privacy. Personal health data acquire not only scientific but also economic value, and it is precisely from this characteristic that derives a danger to which the protection of the patient must correspond (Izzo 2000). The use of electronic devices as a support for healthcare began with the creation of healthcare and administrative back-offices, mainly in healthcare companies, where it was created as an aid to take care of external relations with patients, providers, other companies, to systematize the overall information flows of the healthcare system. It is the task of the attending physician to contribute to this flow of information to allow the identity of the person concerned to be traced for administrative checks, for epidemiological and research purposes or to verify the correctness of medical prescriptions (Buccoliero, Caccia, and Nasi 2005). In the medical field, however, there is a difference and a different extension of the concepts of confidentiality and professional secrecy. The secret is non-specific and subjective and can only be defined in negative terms: it is secret everything that one wishes not to be brought to the knowledge of others. Confidentiality (e. g. sensitive or identifying data) has its own defined subject of protection, i. e. data leading to personal identification, health, sexual orientation and so on. In the forensic field, therefore, the different scope of the concepts of secrecy and confidentiality is relevant. The secrecy, however protected, does not give full guarantee of confidentiality. The disclosure of secrecy may be deemed lawful, and not sanctioned, for just cause of law and, in any case, only concerns the express nature of the subject matter of the secrecy; confidentiality is something else and must be protected within the framework of the individual's right to self-determination in all his or her free exercise of personality. Since the 1990s, the scope of confidential documents has been considerably reduced, leaving room for the category of documents accessible to those with an interest in them. Secrecy has become an exception, justified by the protection of values, to the right to information. Today, the right to information is an essential right for everyone and makes it possible to protect certain spheres of knowledge. This right is an important obstacle to abuses, mismanagement, corruption and, at the same time, facilitates the trust of the citizen who participates in the decision-making process of administrative and management apparatuses that govern and operate according to the principles of administrative transparency. Freedom of information is now beginning to be widely recognised in international law. There are numerous treaties, agreements and declarations of regional and international organizations that oblige or encourage states to adopt laws in this area. Many states around the world have now adopted laws on freedom of information and access. Specific laws guarantee the right of access in certain fields, such as health, the environment and consumer protection. Much of the legislation on the right to information has been adopted over the last 20 years and the new legislation adopts an innovative process to improve access to information. However, the evolutionary path does not end here, as many states remain trapped in the culture of state secrecy and the law is nothing but the mirror of societies that need to evolve on several fronts. The benefits of freedom of information include democratic participation and citizen awareness in public management. In medical science, information is the heart of treatment; in other words, information in many ways coincides with treatment. Medicine is therefore, first and foremost, information from the patient, whether understood in a subjective or objective sense. Every diagnosis presupposes and implies a flow

of data that the doctor must be able to collect, organize and interpret. Moreover, medicine is also (and above all) information on the patient: it becomes such when the physician shares the collected data in order to receive specialist responses aimed at integrating the diagnostic picture, that is, it allows to reduce the relational complexity level of clinical processes, determining the fundamental role that the timely transfer of medical information plays in the perspective of the provision of a treatment that appears to be more and more the complex product of a network work (Aydin 1989). The information thus shared (the patient's clinical history, symptoms, therapeutic treatment, and outcomes) can be archived and made accessible to other physicians, thus becoming "experience" for the scientific community. Once the information on the patient has become a "case", it is objectified, aggregated, and validated according to epidemiological and scientific canons, to become new knowledge to be used for diagnostic and therapeutic purposes. With the meta-analysis procedure of statistical evaluation of aggregate data, Western science seems to approach the potential of the inductive method for the first time. This represents a relevant fact that this revolution in the epistemological method followed by Western medicine, connected to the Cartesian deductive method, could only develop thanks to the advent of ICT. The consolidation of meta-analysis in the medical field, as a method of statistical processing and reading of the results of individual studies, is today the most evident indication of the value that the aggregation of data represents in the development of medical knowledge (Goodman 1999; Trimarchi 2003). One example is preventive medicine. In many international and national health policy documents and directives, prevention means collecting and studying information to quickly delineate the epidemiological development of diseases, and at the same time disseminating information about the care and preservation of health. Prevention means, therefore, guaranteeing the best accessibility, usability, timeliness, completeness and accuracy of information, information "to" the patient "for" the patient. But even when the primary objective is not prevention, but the individual seeking medical care and assistance, information is still an integral part of treatment. This is the profound ethical and social significance underlying informed consent and its recognition as a legal principle coessential to the treatment of the patient and to the respect of his or her subjectivity in the face of care. In the legal field, information on medical activity assumes a key role in ensuring the implementation of patient rights. A role that becomes evident when the evaluation of the health service received by the latter transits through a courtroom. This is the moment in which medical information assumes (or at least: should assume) documentary forms suitable to satisfy the needs of certainty and authenticity required by law. In fulfilling a function other than the one for which it was collected and produced (e. g. clinical), medical information is relevant as documentary data (or set of data) subject to precise rules, which must meet formal requirements aimed at certifying the integrity and completeness of the information contained therein, even when this conflicts with the need for promptness and speed related to the therapeutic task that the information itself, first and foremost, serves to perform.

3. Access to information and informed consent

The right of access to information is not a new concept because it appeared for the first time in the eighteenth century, in the middle of the "Enlightenment" phase. The French Declaration of 1789 refers to the right of access to information in the provisions concerning public contribution: "Every citizen has the right to decide, personally or through his representatives, on the necessity of state contribution, in order to recognize it freely and to know the purposes for which it is used". Since then, several states have taken measures to regulate access to public information. Today, public administrations produce large quantities of documents containing data and information of all kinds. Almost all political and economic information documents are of public source (laws, judgments, economic planning documents, studies and research by public bodies, statistical data, scientific reports, etc.). Public information is therefore an integral and essential component of modern democracies and an indispensable element in feeding

public opinion. Over time, the scope of confidential documents has been considerably reduced, leaving room for the category of documents accessible to anyone with a legitimate interest. Secrecy has therefore become an exception to the right to information and is justified only in special cases and situations provided for by law. The right to information is an essential right and enables certain spheres of knowledge to be protected. Freedom of information is now widely recognized in international law; there are numerous treaties, agreements, and declarations by governmental or supranational organizations that oblige or encourage states to adopt laws on the subject. In medicine, information is at the heart of care and coincides with it. Medicine is therefore, first and foremost, information "from" the patient, both in the subjective and objective sense. Every diagnosis presupposes and implies a flow of data that the doctor must know how to collect, organize, and interpret. In addition, medicine is also information "on" the patient when the doctor shares the data collected to receive specialist feedback aimed at supplementing the diagnostic picture, i. e. it allows to reduce the level of relational complexity of clinical processes, thereby determining the crucial role that the timely transfer of medical information plays in the provision of care, which is increasingly becoming apparent in the context of the provision of care. The complex product of a network work (Fiori, Bottone, and D'Alessandro 1999). The information shared in this way (the clinical history, the symptoms, the therapeutic treatment of the patient and its outcomes) can be treated, stored, and made available to other physicians, thus becoming an experience for the scientific community. This reflection is propaedeutic to the medical practice of "informed consent", which was born in the context of a renewed social culture on the way to understand the doctor-patient relationship, the same that has also influenced the jurisprudence, which has firstly acknowledged and then considered as fundamental the compulsoriness of informed consent. It is no coincidence that an increasing number of patients have taken legal action on the (presumed) professional negligence of the doctor, based in many cases on imprudence and negligence in making the diagnosis or on the failure to carry out in-depth diagnostic tests, as well as on the lack of information and acquisition of consent, thus considerably increasing the number of disputes on this delicate subject. Informed consent is, in fact, the right of the patient to choose, accept or even refuse the treatment (diagnostic-therapeutic) offered to him, after having been fully informed (unless the patient expressly waives) about the diagnosis and expected course of the disease, the treatment options (including their refusal) and their consequences (Preite 2014). However, the issue becomes complex when analysing the effects of telemedicine on informed consent, which also extend to the possibility that the patient receives a benefit derived from the knowledge of other physicians via telematics. The question is whether and to what extent computer technologies applied in the medical and clinical (e-health) fields can improve the cognitive processes by which patients receive the explanatory information that is the subject of informed consent. In the United States, computer-based dissemination systems have long been on the market, which can be delivered by the doctor to the patient to facilitate the learning of the contents of the information accompanying the patient's decision to undergo a particular therapeutic or diagnostic procedure. These systems guide the patient to understand the information received and measure the actual degree of it through test grids, the computer support documents at the end of the path the results of the cognitive process followed by the patient. Moreover, digital technology envisages the possibility of implementing new tools suitable for protecting the patient's self-determination. It can already be assumed that the implementation of digital health cards can provide anyone with the possibility of making their decisions regarding the therapeutic scenarios following a sudden event knowable, with a margin of certainty and security, as well as with a functional versatility in the critical context in which these decisions must be made known to the health authorities, which is completely unknown to traditional paper documents. With reference to informed consent, therefore, e-health represents a further possibility to offer answers to the problem of the uncertain distribution of the burden of proving in court whether (and in what way) informed consent has been given. In the background of the ques-

tion, there is an antagonism between a penalist approach which ends up placing the burden of proof on the doctor (Riz 1990; Nannini 1989) and a contractual approach which produces opposite effects, opening to the patient the difficult experience of proof of a negative fact entrusted to testimonial discussions. Hospital practice has reacted pragmatically to this problem by providing for the use of information forms which must be read, accepted, and signed by the patient. E-health certainly facilitates decision-making between doctor and patient when initiating a treatment or an invasive diagnostic procedure, a decision which can be institutionalised at a different level from what it seems to be today, because of a practice which relies exclusively on the legal value of a signature. Informing a patient is the exclusive task of the practice in modern medicine and cannot be reduced to the simple acquisition of a signature, rather it is necessary to institutionalize and take care of the relationship between the parties involved in the process and thus the moment of doctor-patient communication (Schuck 1994).

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