

# Catholic Reflections on the Privacy of Persons in the Practice of Medicine\*

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contributo

The balancing of individual privacy and the common good has been a topic of debate since the dawn of bioethics. Recent advances in science, medicine and information technology, however, have dramatically increased the potential points of conflict, challenging the basic framework of medical ethics, and along with it, the fundamental nature of the doctor-patient relationship – a relationship based on consent and trust that has stood for almost 2,500 years.

Within the present longitudinal (extended period of time), comprehensive (broadly ranging) and interoperable (easily accessed across vast systems and users) context of modern medicine, privacy and confidentiality may seem at best, lost, at worst, unachievable. Yet, Catholic bioethics have argued that the principles of privacy and confidentiality remain fundamental to the nature of medical care regardless of the ever-expanding practice of data collection and data management. Control of patient data must continue to reside with the patient. Responsibility for patient privacy and confidentiality must continue to fall upon his or her fiduciary, the physician, regardless of arbitrary mandates to sequester information—with or without considerations of proportionate impact and due cause.

Earlier this month, *Science Translational Medicine* published under the headline, *Fetal genome deduced from parental DNA* an article which opened as follows: «Heralding a future in which a child's entire genetic blueprint can be examined for traits and defects — noninvasively — long before birth, researchers have announced that they have re-

constructed the whole genome of a fetus by using only a blood sample from its mother and a saliva sample from its father»<sup>1</sup>.

Without attempting to address the issues respecting the rights and obligations of parents and children, born or unborn, to a child's medical data, the fundamental issue respecting data capture raised by the article above is nonetheless instructive. Genetic blueprints, records that identify our person, and our past, present and future health, once taken from the confidential doctor-patient relationship and given, at times arbitrarily, to entities whose interests *are not bounded by* the professional and ethical oath of the physician, cannot be protected by the patient. Outside of the hands of the physician and free from the binds of patient consent our personal identity, history and map becomes property at the hands of others, often claiming a right to serve the common good, but without the consent or direct benefit to those of us who are compelled to supply it. How is it that the Catholic understanding of the practice of medicine extends so far as to reach the proper collection and handling of personal data? Data itself is not a human subject of moral bearing. As such, should it be beyond the field of Catholic teaching?

In order to formulate a Catholic response respecting the ethical treatment of personal patient data by entities outside the doctor-patient setting, we must consider who and or what is our *subject*.

The data that we are dealing with cannot be treated as mere personal property, such as money or clothing, or simple information such as personal location. It is more than that. It is medical data of *specific personal iden-*



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Studia Bioethica - vol. 5 (2012) n. 1-2, pp. 103-105

tity far more personal even than a person's name and unique facial features—both of which are already accorded great personal protection under current law. The blue print of a person's corporal, emotional, psychosomatic being exists in the records of that person's medical history *and the data and the person cannot be separated.*

The 1995 *Charter for Healthcare Workers*<sup>2</sup> issued by the *Pontifical Council for Pastoral Assistance to Healthcare workers* offers some insight on this point. I quote: «*Health care workers must above all else be aware that each person is a unity of body and soul, and realize that for this reason the person himself in his practical reality becomes achieved through the body*».

What is «achieved through the body», even simple tasks such as picking up a pen, are not just physical actions but rather are *expressions of the person*. Similarly, information on the person's physical, emotional and tempermental being must be awarded treatment of a personal nature as such information is deemed *of the person and not merely by the person*.

The Pontifical Academy for Life document entitled *Prospects for Xenotransplants* elucidates the ethical treatment of personal identity in the following two paragraphs<sup>3</sup>:

«Certainly, the concept of “personal identity” is replete with implications and subtleties of meaning, given the different contributions of philosophy and science we can indicate personal identity as the relation of an individual's *unrepeatability* and *essential core* to his *being* a person (ontological level) and *feeling* that he is a person (psychological level). These characteristics are expressed in the person's historical dimension and, in particular, in his communicative structure, which is always mediated by his corporeality. It must be affirmed, then, that personal identity constitutes a good *of the person*, an intrinsic quality of his very being, and thus a moral value upon which to base the right and duty to promote and defend the *integrity*

of the personal identity of every individual». It is thus fairly clear that as the Catholic Church does not separate the data from the person that Church teaching does not provide, at least under «normal circumstances» for the collection of personal data without consent. Should there, however, be some exception for research purposes? Is, or should there be some basis to discriminate data collection for say, commercial purposes, from data collection for the «common good?» Catholic teaching also speaks to medical treatment and medical research: its aims and its proscriptions. Again, I quote again the Charter:

«[The human person] because of his unique dignity, can be the subject of research and clinical experimentation with the safeguards

due to a being with the value of a subject and not an object. For this reason, biomedical sciences do not have the same freedom of investigation as those sciences which deal with

things. “The ethical norm, founded on respect for the dignity of the person, should illuminate and discipline both the research stage and the application of the results obtained from it”».

«[A patient] should be informed about the experimentation, its *purpose and possible risks*, so that he can give or refuse his consent with full knowledge and freedom. In fact, the doctor has only that power and those rights which the patient himself gives him». Quoting again from the Pontifical Academy: «In the *research* stage, the ethical norm requires that its aim be to “promote human well-being”. Any research contrary to the true good of the person is immoral. To invest energies and resources in it contradicts the human finality of science and its progress. In the *experimental* stage, that is, testing the *findings of research on a person*, the good of the person, protected by the ethical norm, demands respect for previous conditions which are essentially linked with consent and risk».

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What makes a medical act *medical* depends upon several things, including the nature of the doctor–patient relationship. Primarily a medical act is a therapeutic act (therapeutic principle) that seeks the health and wellness (object) of the patient (subject). The professional, ethical, historical norm of confidentiality characterizes the healthcare physician and worker along with the therapeutic principle of action. Any act that utilizes medical technology, expertise or findings and is not practiced true to the character of the doctor–patient relationship cannot be considered a medical act or service. Furthermore, to be medical, an act must preserve the confidential nature of therapeutic service provided to the person who consents to it.

Information contained in the medical records of patients across the country pertain to much more than an individual’s privacy. Healthcare records fall in the nature of personal identity: records *of* a person and not information merely *about* a person.

Notwithstanding the arguments above, no one could argue that the collection, banking, combing and analysis of electronic data, is a secure process. Records are handed on for billing, disease control, pharmaceutical research, marketing, etc... and data is even sold... patient records have become a commodity, not owned by the patient. And the risks to the patient are well known. The 2009 *Report of the Council on Ethical and Judicial Affairs of the American Medical Association*<sup>4</sup> claimed that medical identity theft is the «fastest growing form of identity theft», citing that security breaches are «higher than ever before» due to «complex patterns of collecting and using patient information». Where else is a person’s identity so completely recorded?

Yet, even if the process were airtight, that alone would not be sufficient to justify data collection on the scale we see today, as it still

begs the fundamental questions: to whom does the data belong? And what or whom is to benefit from the collection of personal data? The Church teaches that it must be the patient and, by consent, the good of public health unless the harms outweigh. This is not to say that patient records cannot leave the hands of physicians and attendees, but that the very practice of recording, collecting, combing and movement of patient information, be a process transparent to the individual and his or her primary doctor, which bears the incremental and revocable consent of the patient every step of the way. Elimination, or denial of the right of consent places every human individual, every potential and actual patient, retroactively, that is to say our personal information past, present and future, into the vulnerable state of the mapped, violated and replicated fetus, at the mercy of others, too often having competing interests, to decide for us.

#### NOTE

\* Originally presented at the 2<sup>nd</sup> International Health Privacy Summit - Panel on “Cultural Perspectives on Religion and Privacy”.

<sup>1</sup> «Fetal genome deduced from parental DNA», in *Nature*, 06 June 2012, <http://www.nature.com/news/fetal-genome-deduced-from-parental-dna-1.10797>; last visited June 7, 2012.

<sup>2</sup> Available at: [http://www.vatican.va/roman\\_curia/pontifical\\_councils/hlthwork/documents/rc\\_pc\\_hlthwork\\_doc\\_19950101\\_charter\\_en.html](http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html).

<sup>3</sup> PONTIFICAL ACADEMY FOR LIFE, *Prospects for Xenotransplantation*, September 2001; [http://www.vatican.va/roman\\_curia/pontifical\\_academies/acdlife/documents/rc\\_pa\\_acdlife\\_doc\\_20010926\\_xenotrapianti\\_en.html](http://www.vatican.va/roman_curia/pontifical_academies/acdlife/documents/rc_pa_acdlife_doc_20010926_xenotrapianti_en.html), last visited June 06, 2012.

<sup>4</sup> Available at: <http://www.ama-assn.org/resources/doc/hod/a-09-ceja-opinions-reports.pdf>; June 2009, 218.