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## **EDITORIAL**

## PULCINELLA SECRETS

Pulcinella is one of the most ancient comic characters of the Commedia dell'Arte. He is the stereotypical lazy servant, insolent and chauvinist, sometimes stupid, sometimes clever, always penniless, and absolutely unable to keep any secret. In a typical Commedia dell'Arte plot, the master reveals a secret to Pulcinella, who is under oath never to disclose it. Needless to say, after swearing that he will never divulge it, Pulcinella soon acts in a very different way, telling the secret to everybody he meets. Yet each time Pulcinella discloses the secret, he asks for total confidentiality, pretending that no one else knows it. Sooner or later all characters on the stage know the secret but none of them know that all the others know it. Eventually each one behaves as though she were the sole repository of the secret while the only secret is that there is no secret at all. I often think of the Pulcinella's secret nowadays, when someone evokes the 'medical secret'.

Since the earliest codes of medical ethics, the duty of medical secrecy – the doctor's obligation not to disclose confidences revealed by the patient or any other personal details known in his professional capacity - has been considered an essential ethical principle and a legal obbligation of medical practice, as the assurance of confidentiality and respect for privacy allow patients to disclose personal information necessary to medical care. Medical students are regularly trained in confidentiality, and respect for medical secrecy is mandated by all medical professional codes. To be sure, medical secrecy is often considered a prima facie obligation, which can be overcome when the goals achieved by disclosure are more relevant than the goals achieved by confidentiality (e.g. prophylaxis of communicable diseases). Yet there is a general consensus about the normative value of medical confidentiality, which can easily be justified by sound deontological, consequentialist and utilitarian arguments.

The time when keeping drawers closed and not talking in hospital elevators were the golden rules of medical confidentiality is long gone. The traditional account of medical confidentiality was centered on the patientphysician relationship. Today hundreds of individuals and institutions – general practitioners, hospitals, pharmacies, universities, public health agencies, private health insurances, charities – generate and share information on the patients. In 2006 the US Department of Health and Human Services estimated that approximately 150 people, including medical and nursing staff, researchers, technicians, clerical staff, have access to at least part of a patient's records during a hospitalization. Yet it is the application to medical practice of new information and communication technologies that is having a disruptive impact on medical confidentiality. On June 2011, the US Department of Health and Human Services disclosed on its website all health record security breaches, affecting more than 500 people. Of the compromised health information of 6.74 million individuals, only 6,800 paper records were involved: the rest concerned electronic media. Physical theft and loss of disk drives, memory sticks and lap tops accounted for about 63% of the reported breaches. Unauthorized access/disclosure accounted for another 16%, while hacking was 6%. In UK it has recently emerged that the NHS North Central London Trust lost a laptop containing an estimated 8.3 million patient records, and in February 2011 Information Commissioner Christopher Graham reported that millions of electronic medical records were missing in NHS trusts and hospitals.

These gross security breaches are only the tip of the iceberg. Authorized privacy breaches are still more worrisome. Centralized electronic health records, laboratory information management systems, prescription information systems, patient reminder systems, systems for tracking and managing the movement of patients, health registries, monitoring health programs, clinical decision support systems, are increasingly based on electronic distributed systems which require data sharing and system interoperability. No-one is any longer truly capable of knowing where on the Internet personal medical information is stored, not even in which country and under what jurisdisction, or who can actually access it. For instance, in November 2010, it was revealed that the UK NHS has integrated its web site NHS Choices - 'the online "front door" to the NHS' as they describe themselves - into the Facebook Connect platform to allow users to express interest inpages and share contents with friends. A laudable initiative, with the unintended consequence that the behaviour of all individuals surfing on the NHS website has become public and trackable. The greatest irony is that most provisions for protecting online medical privacy are actually - as Richard Sobel

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<sup>&</sup>lt;sup>1</sup> Commedia dell' Arte was a popular form of theatre based on stock comic characters. Originating in Italy during the Renaissance, the Commedia dell' Arte gained great popularity all over Europe. Pulcinella, whose Italian name means little chicken, is known as Polichinelle in France, Mr. Punch in England, Hanswurst in Germany, Toneelgek in Holland, Petrushka in Russia, and Karagoz in Turkey.

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noticed – 'a disclosure regulation'. Today in most western coutries health information may be disclosed for public health purposes, for law enforcement, for national security and intelligence activities, and, in practice, in case of any emergency declared by relevant public authorities. As a consequence access control systems to electronic medical data are designed in a way that can be always trespassed; they are doors that can be easily unlocked by a number of public and private actors without patients' consent and even their awareness.

'If your data is online, it is not private', states security technologist Bruce Schneier. In the post Wikileaks era, most – if not all – secrets are Pulcinella's secrets, medical secrets do not make an exception. Yet it would be misleading to conclude that Pulcinella's secrets are just false secrets, a parody of confidentiality. On the contrary, Pulcinella teaches us that what makes a secret relevant it is

not its being truly secret, but the way in which it affects and shapes the social action. What really counts is not secrecy per se, but who controls information flows and owns data. Are bioethicists ready to accept this challenge instead of insisting on defending the empty fortress of 'medical confidentiality'?

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Emilio Mordini, MD, trained as a psychoanalyst and philosopher. He was a partner of the Psychoanalytic Institute for Social Research (1986–2001), Professor of Bioethics (1994–2006), and Secretary of the Bioethical Commission of the National Research Council (2000–2004). The Founding President of the Centre for Science, Society and Citizenship (CSSC), he currently serves as a scientific secretary to the Italian Technology Platform on Biometrics, and on the boards of a number of international scientific associations. He has published extensively in academic, peer-reviewed, and non-academic publications, and has edited nine books.