



## In Health Data The Genetic Fingerprints of a Nation

Each of us can decide where to place the limits of our private sphere, with a more or less restrictive approach to the issue. But when it comes to health data, the utmost caution is required, which the Data Protection Act has recognized as one of the most worthy of protection.

*by Mariano Masserini*

"Privacy" can be individually modulated and, on the wave of social media, today seems to prevail a culture of sharing. Let's not forget, however, that the data of each of us, even the seemingly harmless ones, can be commercially exploited, allowing a company, for example, to refine its strategy profitably. Every time we surf the Internet we leave traces of our passage, but who among us knows exactly what Facebook, Twitter, Google or Amazon - and not only them - do with the data collected in this way?

### The Private Sphere

In the past, privacy was very limited: my address, my paper mail and little more. Today, the data concerning a person is much more varied and travels on a multitude of channels. "The law," says Baroum Mrad, the EOC's "Data Mister", "always follows social developments with a certain delay: this is also the case in the field of data protection. Today, however, with the GDPR of the European Union (see window) the protection of privacy and transparency related to the use of personal data have reached a good standard; Switzerland has aligned with the EU and, according to the expert, we can be quite confident for the near future, both in relation to the new fields related to Artificial Intelligence and in the fight against cybercrime. "The user today must be able to have control of his data, it is a Human Right", emphasizes the Data Protection Officer (DPO) of the EOC (Ente Ospedaliero Cantonale – of Ticino).

If we go into the merits of health data, we venture into an even more sensitive category of information, because it concerns our health, one of the most valuable assets of the human being. The health status of an entire community can affect a company, a political group, a state. "This interest can result in a trade - not always legal - with enormous profits, but from which the simple citizen does not derive any benefit, when he is not even damaged.

## **Healthcare Data**

The world of health care has always been characterized by the strong presence of medical confidentiality and professional secrecy in general. But today, healthcare is in a time of great transformation: more and more data are processed digitally, the medical records are destined to be completely computerized and the mass of data managed in hospital servers is growing at an exponential rate. This is why it is important that all this data is stored securely and that the patient is aware of his or her right to access it, but also to limit access to professionals, based on fundamental criteria such as trust and competence. In this sensitive field, the DPO of public health also plays a leading role in Ticino, as in several other Swiss cantons.

"Our main challenge today is of a cultural nature: we must constantly make all users aware of the issues of data protection and privacy, especially in our age so marked by digitalization at all levels". Leaving documents with a patient's first and last name in the office or at the common printer, evoking cases of patients undergoing treatment in the elevator, sending unsafe patient documents via e-mail - these are examples of insufficient awareness.

## **The Technological Challenge**

"Technology can do a lot, but it must be framed in an appropriate organizational context, also to minimize the risk of tampering or data theft". For example, sending an X-Ray images via Whatsapp is strongly discouraged: for this reason, the EOC is introducing its own secure messaging channel. Health data is a bit like the DNA of a country: those who have it know where that country is vulnerable, warns the DPO. For a company like the EOC, the health data it has also allows it to make better decisions for patients. For example, analysis of the mass of data collected may reveal the need for a new service, new care.

## **Covid-19 and Privacy**

The exceptional situation of the coronavirus pandemic required exceptional measures to ensure data protection. A major challenge was that of telework, with the adoption of more stringent technical and organizational measures to ensure complete data protection. But the emergency must not be the pretext to introduce definitive measures that excessively restrict freedom. "Just as we must develop antibodies to overcome the virus," Baroum Mrad points out, "we must also develop antibodies to ensure that the virus is not only protected, but that it is also protected."