One step too far for Danish legendary transparency

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Danish regional health authority have collected data from patients illegally in the past seven years, in a scenario reminiscent of George Orwell’s 1984

Consider the following scenario: You feel a little tired and unfit and you decide to have a talk with your doctor. During the talk, you mention your high consumption of alcohol, your erection problems – along with your personal problems with your wife – and your financial issues. After the talk, the doctor makes notes, recording key problems from the conversation. Then she recommends a blood test and she prescribes some medicine. All this information including the health data, the intimate personal problems, the social references together with the results of your blood tests and all prescribed medicines over the past seven years have been sent to a database and stored under your unique personal identity number. Neither you, nor your doctor, are aware of the way your data has been handled.

How is this possible in Europe today? This is the result of a mandatory programme ordered by the Danish regional health authorities. If you live in Denmark, any information on you has been collected and sent automatically from your doctor’s computer to a central database maintained by a private company. This database contains more than 700 entry codes including categories such as depressed, economic problems, sensation of isolation and alcoholism. The information in the database, which was meant for public research, was also offered to projects financed by private medical companies. At its busiest time, it received 400,000 entries per day, from Danish general practitioners.

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1984 for personal health data

This description may sound like something taken from George Orwell’s novel 1984. But, the Danish General Practice Database (DAMD) was a reality only revealed by the Danish media in September 2014. Since then doctors have protested against the mandatory collection of data. A report from the Statens Serum Institut (SSI), the Danish authority responsible for medical data collection, concluded in November 2014 that the data collection had taken place since 2007. But permission to collect data had only included for diabetes. From 2012, the permission also included: chronic obstructive pulmonary disease, heart failure and depression. This is why the DAMD database was deemed illegal and ordered to be erased by the end of 2014.

Meanwhile, the database can no longer be accessed. “This affects 24 research projects, which were using data from DAMD. Many of them were PhD projects, which now have to be redefined. This is a loss to the development of better medical treatment,” says Janus Laust Thomsen, director of the Danish Quality Unit of General Practice (DAK-E) and the DAMD database. He also refers to an OECD report from 2013 where the DAMD database was highlighted as one of the important instruments for improving the health system. The report states: “Denmark has very good databases on quality of care but the goldmine is only partly exploited.” It also recommends more “cross-quality-register data linkage via unique patient identifiers” and it complains that the database (DAMD) “does not systematically contain procedures.”

Doctors are worried

Henrik Keller, a general practitioner, has written an open letter in a newspaper called Weekendavisen on 27 February 2015, signed by 42 colleagues. The signatories express their concern about the collection of patient data without their consent. “The relationship between patient and doctor was affected negatively by the DAMD database. I feared that I could not write sensitive information anymore when I found out that my notes would be used by third parties without my consent. I did not trust that this information would not be misused,” Keller writes. He adds: “I feel very uncomfortable with this surveillance of my daily work, which has been going on for many years without my knowledge. It reminds me of the East German secret police STASI”.

Keller also complained about the commercial interests in these data from medical and insurance companies, which may not be compatible with the interest of the patients. “In some cases, I know that patients have been contacted by private companies on the basis of their diagnosis and asked if they would participate in experiments and tests. We have no clue how the private companies have achieved access to this information,” writes Keller.

DAMD database to be saved

Just as the database was about to be erased, the National Archives of Denmark claimed that they would store and protect the data. The Minister of Culture, Marianne Jelved, who is responsible for the National Archives defended the decision in a radio interview broadcast on the 8th March 2015: “The Government of a justice based society cannot decide which public archive to preserve or not,” she says. “We have to keep the DAMD database for the future”. She was asked if this was the policy even if the data was collected illegally and her answer was “yes”.

With a European perspective on surveillance of the citizens, Jacob Skjødt Nielsen, head of participation at the Danish Board of Technology Foundation in Copenhagen is involved in a EU-funded research project called SurPRISE related to surveillance and data privacy. “Surveillance is becoming more and more a part of the daily life, but there are broad differences in how it is accepted. In Scandinavia people have a very high trust in society and a strong belief that data can and will be used to improve the society. In countries, where trust in government is less common or where authoritarian regimes have ruled in recent times the collection of data about the citizen is much less accepted,” Skjødt Nielsen says.

One of his colleagues agrees about the difference in perception of surveillance and its potential misuse. “In Spain or Italy we have less trust in institutions. If medical data was collected in a central database most people would fear it would have a high probability of leak or misuse,” says Vincenzo Pavone, an Italian researcher from IPP Institute of Public Goods and Policies in Madrid, Spain who is also involved in the SurPRISE project. On the other hand, people in general...
uncertainty less and there is a tendency that camera surveillance in public places are becoming more accepted,” says Pavone.

The discussion is far from over in Denmark. A recent terrorist attack in Copenhagen made people call for even more surveillance. A survey made for the Danish Broadcasting Corporation DK showed a large majority in favour of a national DNA archive with DNA profiles of all citizens. Similar issues are likely to crop up across Europe, particularly in the context of the new Data Protection Directive, where the jury is still out on how best to regulate the use of personal data for research.

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