



Move to market gene pool angers Iceland's MDs

Patrick Sullivan

Doctors in Iceland are outraged by a government-approved business deal that they say will jeopardize patient privacy. The issue came to a head last December when the Icelandic parliament gave the go-ahead to the creation of a health sector database. The legislation, which was amended twice before being passed, gives a single company a monopoly to create a database that will provide a comprehensive retrospective and prospective collection of medical records that is designed to cover everyone in Iceland.

In a blistering report delivered to the World Medical Association (WMA) in April, the Icelandic Medical Association (IMA) said that even though it recognizes the scientific value of databases, the new legislation "violates basic principles established to allow the use of these resources and at the same time uphold patient autonomy and dignity."

At the root of the issue is a clause granting a monopoly to a private company that would develop the database for commercial use. "The IMA came to Chile for the WMA's April meeting because the country's doctors are so concerned," said CMA Secretary General Peter Vaughan. "It seems to me to be just the sort of issue the CMA's Privacy Code attempts to address."

Vaughan says the Icelandic doctors were given a copy of the CMA code; the WMA responded to their concerns by creating a working group on the privacy of health information. The principles in the CMA code may eventually form the basis of a WMA policy.

In its report to the WMA, Iceland's doctors outlined 7 specific concerns. They include:

- Invasion of privacy: The IMA describes the plan as a "great threat to personal privacy. The data in the database are encrypted but not anonymous; a key is available to connect names to the coded information."
- Breach of patient-physician trust: Iceland's doctors argue that the transfer of medical records to third parties will undermine the confidence between patients and physicians. They fear that patients may withhold sensitive information, increasing the risk of misdiagnosis. They also warn that the value of the database may diminish if the erosion of trust makes the information it contains unreliable.

The IMA is also worried that the government is treating medical records as a commodity, since the legislation gives a company an exclusive monopoly to create and use the database to make money. And there is money to be made. The IMA says the company given the monopoly, deCODE Genetics, has already signed a US\$200-million contract with Hoffmann-LaRoche Inc. for research emerging from the database.

The concerns of the Icelandic doctors aren't shared by Dr. Ronald Davidson, a clinical geneticist at Toronto's

Hospital for Sick Children. Writing in the *Royal College Annals*,¹ Davidson described Iceland as a genetic goldmine because it is "the only homogeneous, isolated, white population in the world. . . . This homogenization of the population creates a genetic background that is analogous to that of an inbred strain of laboratory mice. It has made Iceland a unique and ideal place to perform modern DNA research."

According to Davidson, the island is an ideal spot to investigate the origins of "almost any common disease where there might be a genetic component to the cause."

Although Davidson agrees that the database raises concerns about privacy and the creation of a research monopoly, he notes that it has already created 250 research jobs and "the stimulus that this project has given and will continue to provide to education is of such importance that it overrides most of the risks." As for opposition from the IMA, Davidson says: "Why would it be any different from the CMA or AMA? Historically, medical associations have opposed anything that is new or progressive." He also thinks Iceland's doctors "do indeed overstate some of the problems."

Iceland's physicians remain unconvinced. In their presentation to the WMA, they concluded with a series of questions.

"Is it ethical to sell or give away data from public or private health services to biotech firms without obtaining informed consent from patients?"

"And is it ethical to grant a single private enterprise the exclusive right to create, operate and profit from a comprehensive centralized health database, thus changing a public resource into a private commodity?"

The WMA working group will attempt to answer those and other questions this year. In the meantime, Dr. Michael Yeo, the CMA's director of ethics, remains concerned about the recent developments affecting Canada's North Atlantic neighbour and its 275 000 citizens. "This looks like a very bad idea," he said. "From both the commercial and privacy angle, I hear a lot of alarm bells going off. I don't think Canadians would accept this kind of initiative if it were put to them as starkly as it was in Iceland. However, perhaps something like this could happen gradually without Canadians really taking notice of the small steps along the way. I think the IMA is demonstrating strong leadership by taking this issue to the international community."

Patrick Sullivan is News and Features Editor at CMAJ.

Reference

1. Davidson RG. More genes for sale: the Iceland genome story. *Ann R Coll Physicians Surg Can* 1999;32(4):208-10.