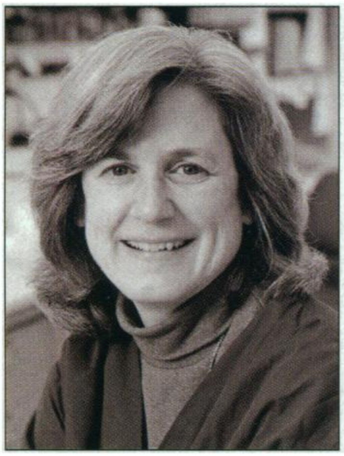
NBAC members also are debating a proposal that would ask the government to create a special committee that could review projects and grant regulatory waivers for research "of exceptional importance."

Despite the issues raised by the NIH fax, observers are betting that NBAC will adopt a report at the November meeting. NBAC is under "a lot of pressure" to move quickly, according to one policy analyst, because its last publication, on the ethics of cloning, appeared in June 1997. **–ELIOT MARSHALL**

HUMAN GENETICS

Opponents Criticize Iceland's Database

A bold plan to establish a database containing the medical records of the entire population of Iceland has generated a furious controversy in the isolated and sparsely populated island itself—but it has caused hardly a ripple beyond Iceland's shores. No longer. Geneticists, bioethicists, and privacy experts from Europe and the United States are rallying against the plan and are urging Iceland's parliament to think twice before approving a bill that would make it possible. They claim that the bill would permit privacy violations that would be allowed almost nowhere else in the world—and may even infringe on Icelanders' human rights.


"Quite troubled." Geneticist Mary-Claire King.

The criticism comes at a time when Althingi, the Icelandic parliament, is preparing to vote on a third version of the Health Database Bill. A first version was sent to parliament in March but withdrawn just weeks later after a storm of protest from Icelandic doctors, scientists, and patients' groups. A second, somewhat qualified draft was sent out for comment to dozens of organizations in late July (*Science*, 14 August, p. 890). The final version, put before Althingi on 9 October, is now under scrutiny by the Health Committee, after a first round of plenary debate.

Under the bill, health records of all Icelanders would be put in a central database. One company, deCODE Genetics in Reykjavik, founded by former Harvard geneticist Kari Stefansson, would be given a 12-year license to operate the database and sell access to third parties. Combined with biological samples and Iceland's detailed genealogical records, the database could be a valuable tool in tracing new disease-causing genetic mutations—a hunt that the Icelandic population is ideally suited for because of its unusual genetic homogeneity.

But even after the most recent refinements, critics still maintain that the bill is unacceptable. They have focused in particular on provisions that would permit people's medical data to be used for research without their informed, written consent. They also argue that safeguards to protect patients' privacy are inadequate and that it is unfair to grant one company use of the data while denying it to outside researchers whose studies might harm that company's commercial interests. Critics in Iceland are now being joined by colleagues from abroad, who Stefansson claims were misled by opponents who "spread misinformation about the bill all over the place."


Privacy concerns. Computer security expert Ross Anderson.

Geneticist Mary-Claire King of the University of Washington, Seattle, together with Henry Greely, a specialist in genetics and the law from Stanford University, recently wrote a letter to the Icelandic prime minister and the ministers of justice, health, and education, urging them to reconsider the plan. Although the idea of a database itself is "positive and exciting," King and Greely write, the current proposal is "quite troubling" in its "treatment of individuals, of the entire Icelandic community, and of science." Richard Lewontin, a geneticist at Harvard University, in a letter published in an Icelandic newspaper, objects to the bill granting exclusivity. Lewontin even says a scientific boycott of Iceland may be called for, "but only provided our Icelandic colleagues agree."

Some of the fiercest criticism, however, comes from Europe. At the request of the Icelandic Medical Association (IMA), computer safety expert Ross Anderson of the University of Cambridge studied the privacy provisions in the proposed new law. He concluded that simply stripping names, addresses, and birth dates from the data is not sufficient: In a country of less than 300,000 people, just a few pieces of data will often reveal a person's identity. The plan would therefore "cause serious conflict" with the ethical principle that identifiable health data must be kept secret unless the patient agrees, Anderson says. Moreover, after discussing deCODE's plans with company officials in Reykjavik, Anderson concludes that the company's "lack of competence at computer security is quite evident." He therefore advised the IMA to oppose the bill. Stefansson dismisses Anderson's criticism as the work of "a hired gun." The IMA, however, "shares Anderson's opinion until proven otherwise," says IMA chair Gudmundur Bjornsson.

Criticism has also come from legal experts. Sixteen of Europe's national Data Protection Commissioners—who oversee data-privacy laws—discussed the case in September during a meeting in Spain. They have urged Iceland's minister of justice to reconsider the plan because it may violate several European treaties, most notably the European Convention on Human Rights—a suggestion Stefansson calls "incredibly outrageous." If the bill becomes law, warns Dutch Data Protection Commissioner Peter Hustinx, Iceland may well risk a conviction by the European Court in Strasbourg.

Within Iceland, meanwhile, the "battle is getting harder," says geneticist Jorunn Eyfjord of the Icelandic Cancer Society. Recently, the IMA has clashed with Prime Minister David Oddsson and deCODE on several occasions. "At the moment, the atmosphere is spoiled," says Bjornsson. "They have tried to make us look unserious and untrustworthy. … But we will have to find a way out of the trenches."

Indeed, many predict a resounding victory for the bill when votes are cast in Althingi next month. Only two members of the two governing center-right parties have declared themselves opposed to the plan so far. But with so much animosity surrounding the venture, implementing the database may be difficult, even if the bill is passed. After all, it is Icelandic doctors who will have to enter their patients' data into the computers. To Bjornsson, a boycott of the data collection, advised by Anderson in his report, is too serious a step. "We can't support breaking the law," he says; "that would be foolish. But it would put us in a difficult position. … We do have basic ethical principles that we won't give up."

–MARTIN ENSERINK

Martin Enserink is a science writer in Amsterdam.

CREDIT (BOTTOM): DAN LAMONT