AIDS RESEARCH

# Netherlands Pulls Top Teams' Funding

Over the past 13 years, a close-knit collaboration of HIV researchers in Amsterdam has turned this city of canals and museums into a highly rated center for AIDS research. But this month the Dutch government announced that it plans to end the group's special funding, a move that scientists from around the world say could jeopardize continued progress against the disease. "This is an outstanding group of investigators," says Anthony Fauci, director of the U.S. National Institute of Allergy and Infectious Diseases in Bethesda, Maryland. "If removing the earmarked money means they won't be funded, that's bad for AIDS research."

The secret of the collaboration's success has been its access to two major groups of HIV-positive individuals in Amsterdam, gay men and intravenous drug users. By tracking these cohorts since the beginning of the epidemic in the early 1980s, the collaboration—led by Roel Coutinho of Amsterdam's Municipal Health Service, Frank Miedema of the Netherlands Red Cross Blood Transfusion Service, and Joep Lange and Jaap Goudsmit of the University of Amsterdam's Academic Medical Center—has helped shed light on a number of features of HIV infection, including the critical finding that different stages of the disease are correlated with genetically distinct variants of the virus. "The accomplishments of the collaboration have been extraordinary," says Fauci. The work has resulted in more than 250 publications—many of which remain among the most frequently cited papers in the field.

In fact, the program's very success has led health officials to cut off earmarked funding for all of the Netherlands' AIDS research, which has amounted to about $40 million over the past 10 years. "The scientific spin-off has been so impressive that there is no need for the health ministry to further finance this program," says Wendy Reijmerink, an AIDS policy adviser to Dutch health secretary Els Borst-Eilers. Reijmerink adds that the program was funded "far longer" than other special projects, and that the Amsterdam researchers must now compete for grant funds along with other biomedical investigators.

While the collaborators knew that they would eventually have to live within a tighter budget, they expected to have at least three more years of special funding before being thrown into the jungle of grant competition. Coutinho says that the government's sudden and unanticipated decision leaves them no time to find other funding to keep their teams intact. "We are left with nothing," he says. "On 1 January, the 60 or 70 people working on the different projects will all have to be fired."

Faced with that prospect, the leaders of the collaboration faxed an emergency appeal last week to 25 internationally known AIDS researchers, asking them to write to Borst-Eilers. "It is particularly unfortunate that the funds should be withdrawn on such short notice, thereby spoiling the careers of young scientists devoted to AIDS," says virologist Robin Weiss of the Institute of Cancer Research in London. The Dutch scientists hope that global pressure will either reverse the decision or buy them more time to make the transition.

**–Michael Balter**

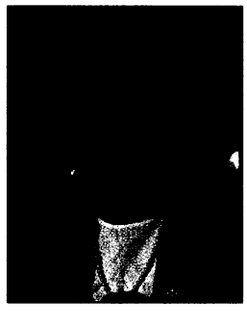
CLINICAL RESEARCH

# Privacy Rules Set No New Research Curbs

Civil liberties groups were upset by a new plan for protecting the privacy of medical records unveiled last week by Health and Human Services Secretary Donna Shalala. They felt the proposal went too far in making exemptions to its strict standard of privacy to aid law enforcement. But biomedical organizations, some of which had worried that new rules might put a new burden on clinical studies, have so far offered no major objections. For the most part, the plan Shalala outlined would leave existing controls on health records essentially unchanged while imposing penalties for misuse of information. But some research groups remain wary: They want to see the fine print before they give their final blessing.

Testifying before the Senate Committee on Labor and Human Resources on 11 September, Shalala laid out a series of guidelines to protect the confidentiality of electronic and paper medical information. She specifically recommended that anyone who improperly discloses information, including researchers, be subject to criminal penalties, and that patients have the authority to sue violators of the rules for civil damages. Researchers would still be able to use health records without patient permission for tracking infectious disease outbreaks. And clinical and epidemiological studies could still make use of data in health records from which personal identifiers have been stripped. But researchers overseeing such projects would have to keep accounts of how data were used, remove identifying information as soon as possible, and not disclose the data further unless needed for additional research.

The proposed guidelines do not deal with one vexing issue: researchers' access to material in tissue banks when patients have not explicitly agreed to their use in research. Shalala noted that the issue is being considered separately by the National Bioethics Advisory Commission.



RICK KOZAK

**Tough sanctions.** HHS Secretary Donna Shalala.

Drug companies and research groups are relieved that Shalala has included genetic privacy within the rubric of medical privacy rather than treating it as a topic to be regulated separately. The president has already suggested ways to safeguard genetic data (*Science*, 18 July, p. 308), but Shalala told the committee, "this builds on but doesn't go beyond that. ... It's important for Congress to address these together and not do it piecemeal." David Korn, a visiting scholar at the Association of American Medical Colleges, who has been critical of other ambitious plans to regulate research data, says "I think that is a logical and correct approach."

Drug companies do have some concerns, however. They're worried that Shalala is setting a "floor" with the national law but that states could enact more restrictive laws, as many are doing in the area of genetic privacy. That could affect "where companies or researchers decide to locate research," says Gary Persinger, of the Pharmaceutical Research and Manufacturers of America. Persinger also notes that because the guidelines do not precisely define what constitutes identifiers, it's not clear whether they would limit research involving anonymous patient data that are linked with a secure key to identifiable data so researchers can obtain more patient information if necessary.

Several proposals in Congress will go much further than Shalala's report does. For example, Senator Patrick Leahy (D–VT) plans to introduce a bill that would require patient consent for research use of any health records. Leahy issued a press release describing the proposal to allow use of some records without consent and others with identifying information removed "troubling." The Labor Committee plans another hearing on the topic later this month, and many more are likely to follow. As Shalala said, "This is the beginning of a long discussion with the Congress."

**–Jocelyn Kaiser**