

# East German Cancer Data: A Benefit of Big Brother?

*A detailed database put together by totalitarian East Germany may tempt the new Germany to relax privacy laws*

**Berlin**—THE FORMER EAST GERMAN GOVERNMENT was notorious for spying on its own citizens. So detested was this official snooping that, when revolution came to East Berlin, the protesters' first target—after assaulting the Wall with sledgehammers—was the headquarters building of the Stasi—the secret police—and its vast records. But among the old East German government's files was one set of data that medical researchers now find themselves fighting to preserve: a huge array of epidemiological information, gathered since 1957, on more than 2 million cases of cancer—95% of all the cases that occurred in East Germany.

Researchers would dearly love to mine this lode to extract information on possible links between cancer and exposure to carcinogens, but they have hit a serious roadblock. Under the Federal Data Security Act—now valid throughout Germany—the cancer register is illegal. The law, which reflects public fear of a return to the totalitarian past, allows medical records bearing individual names to be kept only for very specific purposes, narrowly defined in advance. It has greatly hampered epidemiological research in West Germany; there is no way, for example, to retrieve past records of disease incidence and match them to other records—such as lists of employees in a particular industry. “From a strictly legal point of view all the data [in the cancer register] should be erased,” says Gabriele Hundsdörfer, who heads the cancer abatement division of the federal ministry of health in Bonn. “There is no legal basis for the cancer register anymore.”

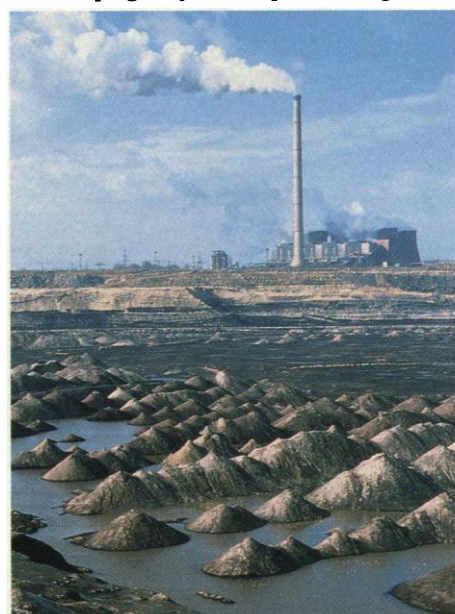
The possibility that such a valuable resource could be lost has sparked an effort to change the law, not just to permit the register to be retained but to allow new data to be added to it from the five states (plus the city state of Berlin) that once made up East Germany. If successful, scientists hope that further legal changes will allow the new cancer register to be copied by other German states. In the meantime, however, all the records and magnetic tapes of the old East German cancer register are locked away in the Institute for Cancer Research of the Academy of Science in Berlin, with access denied to everyone.

What makes the register so valuable for research—and so sensitive—is the detail with which the cases were recorded. The records include individual patients' personal identification numbers; their full names and birth dates; details of the tumors, including classification and histology; and information on the patients' families and earlier diseases.

The East Germans could not fully exploit the register, explains Matthias Möhner, head of the team that built it up, chiefly because they lacked computer equipment. Only in the 1980s, with help from international organizations, did they begin to make progress. Their initial analyses turned up a few surprises. A study conducted in 1988, for example, apparently showed no higher incidence of lung cancer in regions of highest industrial pollution—the triangle Halle-Leipzig-Bitterfeld is notorious for its air pollution—than in the northern resort areas of Mecklenburg, where the air is exceptionally clean.

High on the list of priorities for the future are more detailed studies of possible relationships between the old East Germany's industrial pollution and the incidence of cancer. Lung cancer rates appear to be significantly higher in the district of Aue, a center of uranium mining, Möhner points out. “We would like to take this on,” he says, “the question is, Will they let us?”

**Cancer connection? Industrial pollution near Leipzig may show up in the register.**



Patrick Piel/Gamma Liaison

Even those concerned with protecting East Germans' newfound right to privacy recognize the potential medical importance of the information. Alexander Dix, Berlin's deputy ombudsman for data protection, accepts what he calls the “high scientific value” of the register. But, he says, “the data must be made anonymous.”

Researchers are concerned, however, that removal of personal details from the records would sharply reduce the scientific value of the information. So, instead of accepting that the register should be neutered, they are hoping that a “Sicherungsgesetz”—a federal protection bill—can save it. The first move must come from the Science Council, the key science advisory body for federal and state governments, which is readying recommendations from a panel of experts.

The Science Council is likely to back continuation of the register, panel member Jürgen Wahrendorf, an epidemiologist at the German Cancer Research Center in Heidelberg, told *Science*. He favors a “registration right” for physicians that would allow them to continue providing cancer data to the register “without having to ask their patients for consent.”

That option, however, is vigorously opposed by the powerful Hartmannbund, the professional society of physicians in Germany. It is arguing for strict confidentiality and wants to retain the legal requirement that physicians receive individual patients' consent before giving their records to the register. But that requirement raises problems: Physicians often cannot ask for consent because they do not want to tell their patients that they have cancer. In West German states that have tried to gather epidemiological data by consent, the return of information is “dramatically low,” Wahrendorf says. “You cannot obtain a reliable spectrum of cancer incidence this way,” he stresses.

Wahrendorf's committee will give its recommendations to the government in July. The fate of the register will then be in the hands of the politicians.

The outcome—and especially public reaction to it—will have broad implications for epidemiological research in Germany. The federal health ministry has already drafted two alternative versions of a cancer register framework law that would apply to the whole of Germany. One version would grant registration rights to physicians, the other would require patient consent. “Which one will be the political choice remains to be seen,” says Hundsdörfer. But with battle lines already sharply drawn, she does not expect a quick decision.

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