

HOW AIDS CASES ARE KEPT STRAIGHT -- AND KEPT ANONYMOUS

By Simson L. Garfinkel

When the AIDS outbreak was first recognized in 1981, the U.S. Centers for Disease Control in Atlanta maintained a list of all diagnosed cases by name. The purpose of the list was to make sure that the same individual was not counted twice if reported by two different state health departments.

By 1982, with more than 200 known AIDS cases, the center recognized the threat to privacy that the list created. At the same time, there was a pressing need to have an accurate count of the number of cases.

Since 1982, cases of AIDS reported by state departments of health are referenced not by name (or Social Security number) but by Soundex codes, according to Meade Morgan, chief of the Statistics and Data Management Branch of the Center for Infectious Diseases' AIDS program. The Soundex code consists of a letter, the same as the first letter of the last name of the AIDS' patient, and a four-digit number derived from the remaining letters in the person's name.

When new AIDS reports are received, a computer at the centers scans a special file to see whether there has already been a report with the same Soundex code. The file of Soundex codes is secured by a password different than the one for the rest of the AIDS database, Morgan said. If the computer finds a match, it then compares the date of birth of the new report with the date of birth in the case on file. If both the Soundex code and the date of birth match, the computer assumes that the second report is a duplicate.

In the majority of cases, the assumption is valid. When there were 20,000 AIDS cases on file, the centers attempted to verify that Soundex/DOB matches were in fact the same individual; this was done by telephoning each board of health and, by a conference call, having doctors in each state exchange the victim's names. Only 20 individuals out of 20,000 cases were found to have the same Soundex and date of birth but in fact to be different persons. Since then, the AIDS program has discontinued this checking procedure because there are simply too many new AIDS cases with which to cope.

The staff people in Atlanta don't use other identifiers to reduce further false matches because they can't be assured to be unique, Morgan said. Even the sex of a person may have changed; some persons with AIDS are transsexuals.

Robert Boruch, a professor at Northwestern University and the author of Assuring (Continued on page six)

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The Writing's on the Stall -- Advertising invading the sanctity of the bathroom?

Yes, according to Stallwords, a Florida agency that has begun selling ad space on the inside doors of airplane lavatories. TWA is the first airline to install the panels, and complaints have been few.

"The only way not to read our ads is to close your eyes," Stallwords' president told Target Marketing magazine. He points out that frequent flyers won't glance through in-flight magazine ads on each flight, but they can't avoid looking at the lavatory door with undivided attention on several occasions.

Personnel Changes -- Jay Plager, associate director of the Office of Management and Budget for Human Resources, has become Administrator of OMB's Office of Information and Regulatory Affairs, which is supposed to oversee compliance with the Privacy Act of 1974 by federal agencies. Plager was a professor of law at Indiana University. * * * The former mayor of Sherbrooke in Canada has been appointed to a five-year term as chair of the Commission d'access a l'information du Quebec, the province's freedom of information-privacy office. Jacques O'Bready, a 58-year old lawyer, had been deputy minister for municipal affairs in Quebec. * * * Alfred Einwag last month became federal data protection commissioner in the Federal Republic of Germany, upon the retirement of Reinhold Baumann.

Agenda -- The American Society for Industrial Security will include computer security issues in its 34th annual seminar in Boston Sept. 26-29. In the Hyatt Regency Tampa Oct. 24-27, ASIS is also holding a Telecommunication Security Workshop intended for telecommunications and security professionals. The Electronic Communications Privacy Act will be discussed. Information from ASIS, 1655 N. Fort Myer Dr., Suite 1200, Arlington, Va. 22209.

A conference comparing Ontario's freedom of information and privacy protections with other jurisdictions will be held Nov. 22-23 in Toronto. Speakers include the chair of the provincial Management Board and the Information and Privacy Commissioner. Information from Janet Halse, FOI and Privacy Branch, Management Board Secretariat, 18th floor, 56 Wellesley St. West, Toronto, Ont. M7A 1Z6, Canada, 416/586-2187.

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the Confidentiality of Social Research Data, called the Soundex code "a numerical alias which can't be decrypted for practical purposes."

The only way to "decrypt" the Soundex code, Boruch said, is to make a list of every possible name that might be encrypted to produce the same code. But since many different names will encrypt to the same code, it is impossible to know which name the Soundex code actually stands for.

"My name, for example, using their encryption scheme produces an alias which, if you tried to decrypt it, you would come up with about 8000 possible names, at a minimum," he said.

Boruch said that it would still be possible to use information such as race, age, blood type and so forth -- often called "collateral information" -- to reduce further the possibilities of identifying an individual by Soundex code. But he does not think this likely:

"It's a whole lot of effort for very little payoff," he said. "I guess if I were an intruder I would try a more direct way to get identifiable information. Theft of records is, I suspect, a bit more direct, even if it is illegal."