

New York's scheme to track diabetes stirs privacy concerns

Responding to skyrocketing rates of diabetes, New York City in January launched a massive project to track people with the disease through a city-wide database. The program reflects a shift in emphasis from monitoring infectious diseases to chronic diseases such as diabetes and cancer.

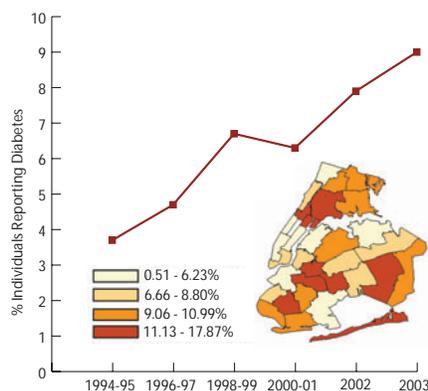
Many hospitals and insurance organizations already monitor rates of diabetes, but experts say New York is the first to track the disease on a city-wide basis.

Despite New Yorkers' reputation as fervent walkers, the city is replete with the ingredients for a diabetes epidemic. It houses a large group of the poor and obese, and immigrants and ethnic groups such as Native Americans and African Americans, whose heredity makes them disproportionately at risk for the disease.

About nine percent of New Yorkers suffer from diabetes—twice as many as ten years ago, according to estimates from the city's health department. If the New York program makes a difference to its citizens' health, it could have a far wider impact, experts say.

"My bet is that if New York was successful, others would follow," says Richard Kahn, chief scientific and medical officer at the American Diabetes Association (ADA).

Individuals with diabetes must keep their blood sugar levels low to prevent serious complications such as heart disease, stroke, blindness and kidney failure. The ADA recommends that those levels be tested up to four times each year with a test called A1c, which



Bitter news: Diabetes is on the rise in New York.

measures average blood sugar levels over time.

Under the new program, each time someone gets an A1c test, the lab will electronically send the results to a central database run by the city's department of health. The data would then help alert doctors about individuals with dangerously high blood sugar levels. The city is also considering a scheme in which it would remind the doctor to send letters notifying individuals of their test results.

It is likely to take several months before labs routinely send results to the database and more than a year before city officials can draw any conclusions. The city does not yet have the money to cover the costs of the program, but is applying for grants from the US National Institutes of Health and from

private sources.

New York has always been a pioneer of disease tracking. In the late 1800s, it became the first to monitor tuberculosis. Soon other towns in the US and UK began requiring physicians to report infectious diseases such as cholera and smallpox. In the 1960s and 1970s, after deaths from infectious diseases had fallen, they added chronic diseases to their repertoire.

Many of those surveillance programs provoked outrage from ethicists who said they were a breach of privacy. New York's diabetes plan has raised similar concerns about privacy and a clear lack of informed consent.

Under the new program, labs that collect the data are not required to inform individuals that their results are being sent to a database. Participation in the database is mandatory for anyone who chooses to take the test.

Concerns about privacy are not entirely unfounded. In 1996, a Florida health official anonymously leaked nearly 4,000 names of HIV-positive individuals to two local newspapers. Although the newspapers did not print the names, the incident serves as a reminder of the potential for leaks.

Still, many experts say the benefits to the public outweigh privacy risks. New York City has used an electronic monitoring system for years to track rates of cancer, communicable diseases and lead poisoning, officials note, but they've never yet had a security breach.

Emily Waltz, New York

Powerful new database pins down emerging infections

A massive new database promises to help scientists identify and fight emerging viruses.

Columbia University researcher Ian Lipkin created the Greene Viral Database to help researchers develop diagnostic methods, vaccines and drug-resistance tests for emerging infections. Lipkin has already used the database to design genetic tags that can rapidly identify outbreaks of the Marburg virus and to pinpoint the genetic segment that allows filoviruses, a subset of the Marburg family, to escape immune detection.

Lipkin's creation draws on two heavyweight collections of data on viruses: the Universal Virus Database, published by the International Committee on Taxonomy of Viruses (ICTV), and GenBank, the storehouse of all public genetic sequences, run by the US National Institutes of Health (NIH).

The 14-year-old ICTV database meticulously catalogs the evolutionary relationships

of all known viruses to each other. Experts curate the information in the database and publish its contents in a book every few years.

GenBank, in contrast, contains viral DNA snippets of varying length and quality from all over the world. Some entries contain partial sequences of specific genes; others list more detailed information. But because GenBank is not moderated by anyone, it's difficult to perform rigorous analyses of its contents. Some viruses are called by different names in different entries, for example.

Lipkin has built up the Greene database over the past five years and says it combines the power of the ICTV's detailed map of the virus relationships with the rapid, global reach of GenBank. "It's already yielded a template for diagnostic tools which we think is very powerful," he says.

To test the power of his resource, Lipkin has sent a viral genetic chip that aims to identify

the 1,845 vertebrate viruses listed by the ICTV to several labs worldwide.

The Greene database provides more than just the sequence of a given DNA sequence; it also makes it possible to discern the geographical distribution of a virus and who first isolated it, notes John MacKenzie of the Curtin University of Technology in Perth. MacKenzie's lab is interested in getting the chips to identify pathogens harbored by Australia's unusual flora and fauna.

The chips are free, but the database is only accessible to members. Lipkin says he hopes to change that with more constant funding. The database cost \$3 million to build and takes about \$500,000 per year to run. Funds have come from both private and public sources, including the NIH and the Jerome L. Greene Foundation, after whom the new virus database is named.

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