



## Facing the Diabetes Epidemic — Mandatory Reporting of Glycosylated Hemoglobin Values in New York City

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The diabetes epidemic in the United States continues unabated, with a staggering toll in acute and chronic complications, disability, and death. The primary culprits are poor glycemic control over

the long term and other major risk factors, such as hypertension, cigarette smoking, obesity, and elevated levels of cholesterol or blood lipids. Although physicians know how to treat diabetes in individual patients, overall progress against the epidemic requires widespread improvement in glycemic control, as underscored by the recent finding that intensive insulin therapy reduces the risk of cardiovascular disease among patients with type 1 diabetes.<sup>1</sup> In 2005, an estimated 20.8 million persons in the United States, or about 7 percent of the population, had diabetes, although the illness had been diagnosed in only about two thirds of these people, ac-

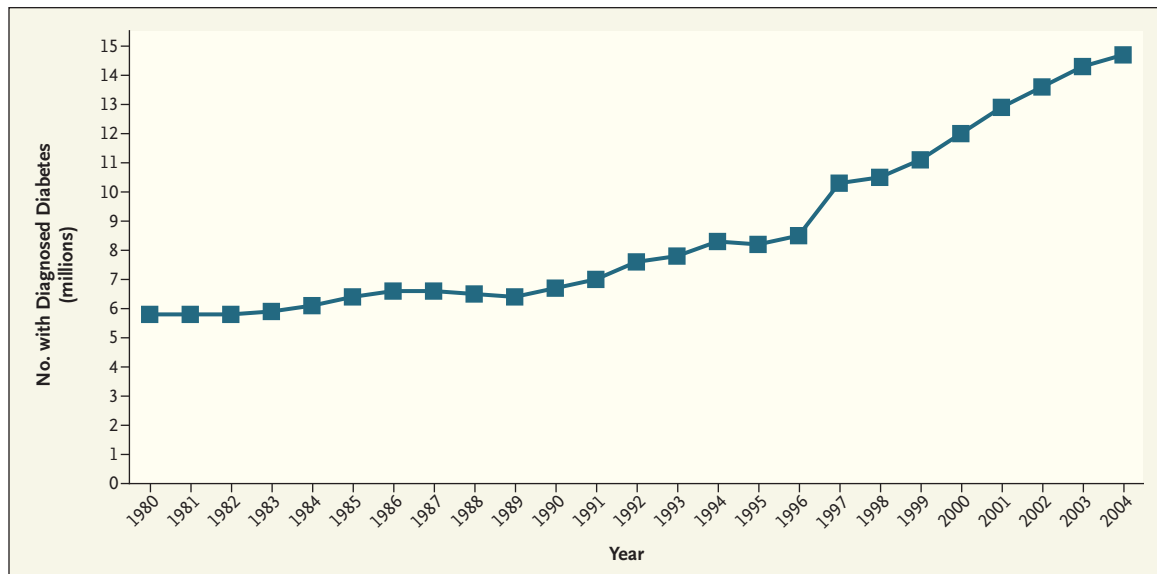
ording to the Centers for Disease Control and Prevention (see line graph). Older people, blacks, Hispanics, and members of some other ethnic groups are disproportionately affected.

Diabetes is the sixth most common cause of death in the United States and was the fifth most common cause in New York City in 2004. In December 2005, the New York City Board of Health approved a novel response to the diabetes epidemic: mandatory electronic reporting of glycosylated hemoglobin values by laboratories to the city's Department of Health and Mental Hygiene. The requirement, which took effect on January 15, 2006, was promulgated under the

department's statutory authority to report and control chronic diseases and to regulate clinical laboratories.

The endeavor has aroused concern about patients' privacy and raised questions about the role of health departments. However, Thomas Frieden, the city's health commissioner, said the aim is to respond to an epidemic of a chronic disease with the type of surveillance and other tools that health departments routinely use to prevent and control communicable diseases. As he explained in an interview, "We have to get a better handle on what is really the only major health problem in the United States that is getting worse, and getting worse rapidly."

There are an estimated 530,000 adults in New York City with diagnosed diabetes. About 9 percent of adults report having received a diagnosis of diabetes; in the



**Number of Persons with Diagnosed Diabetes in the United States, 1980–2004.**

Data are from the Centers for Disease Control and Prevention. The increase in the number of cases between 1996 and 1997 reflects a redesign of the National Health Interview Survey.

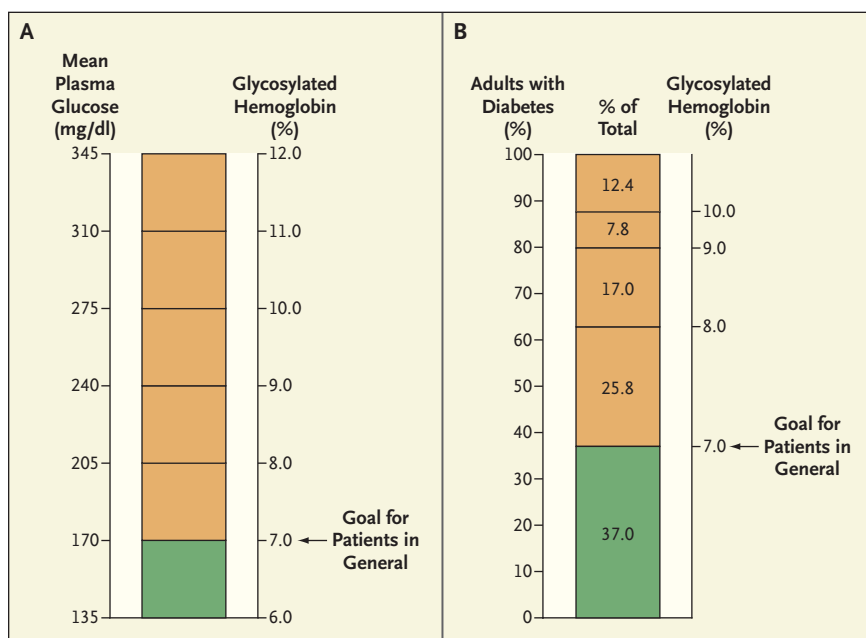
South Bronx, the prevalence of diagnosed diabetes is 18 percent. When it comes to chronic diseases, says Frieden, public health officials have been “asleep at the switch.” His view, as expressed in a 2004 editorial in the *American Journal of Public Health*, is that “local health departments generally do a good job of monitoring and controlling conditions that killed people in the United States 100 years ago. Yet noncommunicable diseases, which accounted for less than 20 percent of U.S. deaths in 1900, now account for about 80 percent of deaths. Our local public health infrastructure has not kept pace with this transition.”<sup>2</sup>

New York City will create a registry of glycosylated hemoglobin test results — an estimated 1 million to 2 million results per year — that is linked to identifying information about the patients and about the physicians who ordered the test. The data will include the full name, date of birth, and address of the person tested and the

date the test was performed. The registry, which will be funded by the health department, will be used to map the epidemiology of hyperglycemia and to monitor the epidemic. Says Frieden: “We should know how many New Yorkers have diabetes that is badly out of control, where they are, and who cares for them. This knowledge should be very powerful for assessing how we are doing on a population basis and in reaching out to doctors and, through doctors wherever possible, to their patients to provide more support.” Starting in July 2007, the department also hopes to implement and evaluate a pilot intervention program in the South Bronx, which would be funded through grants. Eventually, there may be additional uses for the registry data.

The glycosylated hemoglobin value is the primary target for glycemic control.<sup>3</sup> The American Diabetes Association recommends that the blood test — which measures the average level of glycemia over

the preceding two to three months — be performed at least twice a year in patients whose treatment goals are being met (and who have stable glycemic control) and quarterly in patients whose treatment has changed or whose goals are not being met. The goal for patients in general is a glycosylated hemoglobin value of less than 7 percent, and the goal for each individual patient is as close to normal (less than 6 percent) as is possible without clinically significant hypoglycemia (see bar graph).<sup>3</sup> Unfortunately, these goals are often unmet. In 1999 and 2000, only 37.0 percent of adults 20 years of age or older with diagnosed diabetes nationwide were estimated to have values below 7 percent.<sup>4</sup> Moreover, many people with diabetes do not know their glycosylated hemoglobin values, either because they have not been tested or because they have not been informed about their results or do not recall them. In New York City, 89 percent of adults with diag-



**Correlation between Glycosylated Hemoglobin Levels and Mean Plasma Glucose Levels (Panel A) and Distribution, in 1999 and 2000, of Glycosylated Hemoglobin Levels among Adults 20 Years of Age or Older with Previously Diagnosed Diabetes (Panel B).**

The goal for patients in general is a glycosylated hemoglobin level of less than 7 percent, and the goal for each individual patient is as close to normal (less than 6 percent) as is possible without clinically significant hypoglycemia. Data on correlations are from multiple testing performed over a period of two to three months in the Diabetes Control and Complications Trial.<sup>3</sup> Data on the distribution of values among adults with diabetes are from the National Health and Nutrition Examination Survey.<sup>4</sup>

nosed diabetes do not know their glycosylated hemoglobin values, according to a survey the health department conducted in 2002.

The New York City program involves only electronic reporting of glycosylated hemoglobin values that are transmitted by a file-upload method — not case reports from physicians. The requirement covers all tests performed by laboratories that report results to the health department through this electronic means, regardless of how frequently the tests are obtained and whether the person tested is known to have diabetes. Separately, the health department has mandated electronic transmittal, by July 1, 2006, of all required reports, such as blood lead levels and results of tests for com-

municable diseases. By later this year, the department expects to be capturing 80 to 95 percent of the results of glycosylated hemoglobin tests that are performed among city residents.

In the South Bronx, there are an estimated 48,000 adults with diagnosed diabetes and about 270 clinicians who care for them. Many of these clinicians use paper medical records and send blood tests to multiple laboratories, making it difficult to track the test results of their patients with diabetes. The pilot intervention program will be modeled on the Vermont Diabetes Information System, a registry-based decision-support and reminder system funded by the federal government, which is targeted to primary care physicians

and their patients with diabetes. Clinical laboratories throughout Vermont electronically submit data — not just glycosylated hemoglobin values but also other laboratory data that are used in managing diabetes. The program involves 10 hospitals, 121 primary care providers, and about 7350 patients in 55 primary care practices in Vermont and New York. It is being evaluated in a randomized, controlled trial to determine the effect of the information system on diabetes control as measured by glycosylated hemoglobin values. Results are expected this year.<sup>5</sup>

In the South Bronx, 12,000 adults are estimated to have glycosylated hemoglobin values of more than 9 percent. This group of patients with diabetes who have poor glycemic control is considerably larger than the number of all patients with diabetes in the Vermont trial. Although the program is still being developed, the plan is to provide physicians in the South Bronx with a quarterly roster of their patients, stratified according to the level of glycemic control, along with best-practice recommendations for diabetes care. Participating physicians may also receive notification about patients who are due for follow-up tests but have not received them.

Patients may receive a letter if their glycosylated hemoglobin value is above a certain level (the level has yet to be decided), along with educational and resource materials. According to Frieden, concern about privacy will be addressed by “having a very easy opt-out policy. If people don’t want to hear from us, they will never hear from us.” Their test results and identifying information, however, would remain part of the registry. The city health code, as

amended in December 2005, states that glycosylated hemoglobin test results and other identifying information “shall be confidential and shall not be disclosed to any person other than the individual who is the subject of the report or to such person’s treating medical providers,” with the exception that information about a minor may be disclosed to a parent or legal guardian. Thus, the information should be unavailable for other purposes, such as to make it more difficult for a person with diabetes to obtain or renew a driver’s license, health insurance, or life insurance. However, concern about privacy and confidentiality will remain, at least until the registry is fully operational and the health department is able to demonstrate that there have been no substantial breaches.

A disease registry is not a substitute for effective medical care for individual patients. New York

City is unlikely to replicate the sorts of disease-management programs for patients with diabetes that have been established by large health care organizations with sophisticated information systems and ample financial resources. Although the health department may help to facilitate diabetes care — for example, by providing patients with smoking-cessation programs, blood-pressure cuffs, glucose-test strips, or low-cost medications — its resources are limited. At present, the health department has only three staff members and a \$950,000 annual budget dedicated to diabetes control. Nonetheless, the perfect does not need to be the enemy of the good. If the city’s information system works well and patients’ confidentiality is maintained, the registry initiative could be a first step toward other effective — and no doubt more costly — interventions.

An interview with Dr. Thomas Frieden, New York City Health Commissioner, can be heard at [www.nejm.org](http://www.nejm.org).

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#### BECOMING A PHYSICIAN

## The Demise of the Physical Exam

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One afternoon, at the beginning of my first clinical clerkship in internal medicine, my team was called to the intensive care unit. A patient, whom I’ll call Mr. Abbott, had just been admitted with excruciating chest pain that had started a few hours earlier. He was in his early 50s, extensively tattooed, just the sort of tough I wouldn’t want to meet alone in a parking lot at night — but right then he was whimpering. He kept stroking his sternum up and down, as if trying to rub the pain away. It was obvious that he was hav-

ing an acute coronary syndrome. He had all the classic risk factors: hypertension, high cholesterol level, a history of cigarette smoking. His electrocardiogram showed T-wave inversions characteristic of ischemia. His serum troponin level was elevated. I don’t recall our examining him, but for this most common type of cardiac emergency, there is little diagnostic role for the physical exam.

A few hours later, we were paged back to the intensive care unit. Abbott was now writhing in pain, and his blood pressure

was dropping. The resident heading the team — a star of the internal medicine program — had a nurse get an electrocardiograph. He ordered an intern to prepare to insert a catheter into Abbott’s radial artery. Then he asked for an intubation tray. “Check his blood pressure,” he told me.

I had measured blood pressure only a few times, mostly in my classmates. I carefully wrapped the cuff around Abbott’s left arm and inflated it. Then I let the pressure out slowly, listening with my stethoscope at the bend of his