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As stated in the Public Notice of Adoption of Amendments to Sections 13.01(b) and 13.03(c) of the New York City Health Code, city residents are permitted to submit written comments on this proposal. I am hereby submitting my written comments on the proposal as a New York City resident, as well as a patient with diabetes and a Juvenile Diabetes Research Foundation advocate.

As a patient with autoimmune-mediated (better known as Type 1) diabetes, I believe the city's plan to mandate involuntary participation in this registry via electronic lab reporting of hemoglobin A1C tests violates patients' fundamental right to privacy. For patients who are already doing a good job of managing their condition, this plan is nothing more than unnecessary and unreasonable government intrusion into their private medical records, which is prohibited by the U.S. Bill of Rights, as well as clauses in several U.S. Constitutional Amendments. Because this plan does not offer patients the right to have their information excluded from the registry, the plan requires further modification prior to being approved.

Unlike data collection that is used for epidemiological research, this plan contains personally identifiable information that would be used to follow-up on patients but not provide any treatment. Patients will also NOT be afforded the right to be excluded from the registry until AFTER their personal information has been already seized and their privacy has already been invaded. Patients should be offered an option to "opt out" of having their results included in the registry every time the tests are conducted. This can be accomplished by providing a simple option to "opt out" on the order forms used by the labs. This would resolve any concerns about patient privacy, but the city insists that they have already taken privacy precautions. According to the New York City Department of Health and Mental Hygiene, "the registry will have strict confidentiality standards, limiting information solely to patients and their treating clinicians." In addition, they also claim that the city will not provide the information to other agencies, such as the motor vehicle division or insurers, and will not release data to others "even with patient consent." Unfortunately, these assurances are insufficient. Recently, there have been a number of high-profile cases of data security breaches that have occurred among organizations far more accustomed to handling electronic data than city employees. If the private sector has had such problems, assurances from a department with relatively little experience handling such data then promises alone will not be sufficient to allay these concerns.

While health departments already routinely collect health data on HIV, tuberculosis, or lead poisoning, those conditions pose a serious public health risk for not intervening. Unlike those conditions, diabetes is not contagious so there is no fundamental public health risk involved. The motivation behind this plan is economic, not one of public safety.

Even more troubling is the evidence, or rather the lack thereof, presented by the New York City Department of Health and Mental Hygiene for its proposed plan made in the presentation by Dr. Lynn D. Silver and Dr. Diana K. Berger. That presentation implies that forcing patients with diabetes to forego a reasonable right to privacy is justified for their own good and that such a registry will improve patient outcomes. Unfortunately, the reality is that the city's plan will likely do very little in saving the city money or improving patient outcomes because the assumptions backing its A1C Tracking Plan are fundamentally flawed.

Much of the analysis makes comparisons between the National VA Diabetes Registry and to a much lesser extent, the National Institutes of Health-funded Vermont Diabetes Information System (VDIS). The conclusion is that the City of New York might expect similar results simply by implementing a registry. Unfortunately, these assumptions overlook a vital element, namely that the Veterans Health Administration (VHA) provides virtually free or minimal cost treatment to patients on its registry, including testing supplies and medications for its patients at VHA health centers while NYC will

NOT be doing the same. Therefore, the expectation that the city's plan can accomplish the same simply by mailing letters to doctors is unrealistic.

The city's plan to follow-up on patients with reminder letters to their doctors and/or the patients themselves is unlikely to accomplish much in the way of intervention. The reason: most doctors already know better than anyone what acceptable diabetes control should be, but they are powerless to force patients to comply. Reminder letters also will not provide patients with costly doctor's care, medications, expensive testing supplies or the labwork that many of the low-income patients in the areas initially being targeted by the city (beginning with the South Bronx) lack. A lack of health insurance coverage or money to pay for necessary labwork, doctors visits, medicines, etc. is the more likely to the reason many patients with diabetes do not maintain ideal control, and friendly reminder letters to their doctors or to the patient from the city Health Department will do nothing to resolve that fundamental issue.

The City Health Department needs to reconsider its plan and offer patients the right to be excluded from its ill-conceived A1C registry up-front, as well as each time tests are conducted. In doing so, they will resolve the privacy issue and enable the city to implement its "intervention" plan, however flawed it may be without requiring patients to give up a fundamental right to privacy. Patients with diabetes deserve nothing less.

Regards,
C. Scott Strumello