the lessons that can be drawn from this experiment. For example, the results are naturally specific to the study's population, insurance plan, and health care environment. Coverage by private insurance, in different settings, or of people with very different characteristics than those who enrolled in Oregon's Medicaid program might have very different effects. Moreover, the Oregon lottery insured only 10,000 adults. The system-level effects of insuring millions of people at once, including strain on the provider network and any changes in the delivery of care, might be quite different. In addition, our current results cover only the effects of the first year of insurance coverage. The long-run costs and benefits of Medicaid coverage may well be different.

That said, we believe that these results provide the best evidence to date on the effects of Medicaid expansions. Our results cast considerable doubt on both the optimistic view that Medicaid can reduce health care spending, at least in the short run, and the pessimistic view that Medicaid coverage won't make a difference to the uninsured. We expect ongoing data collection to provide even more information about the longer-run costs and benefits of Medicaid coverage.

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# HIV Surveillance, Public Health, and Clinical Medicine — Will the Walls Come Tumbling Down?

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The centrality of antiretroviral therapy for people with human immunodeficiency virus (HIV) infection is an established feature of the clinical response to HIV–AIDS. Now there is compelling evidence that such treatment can have a profound impact at the population level by reducing viral loads and hence infectivity.[1] As a consequence, important ethical and operational questions about the relationship between clinical medicine and public health are surfacing. Perhaps the most fundamental of these centers on the uses of surveillance.

More than two decades of battles over HIV surveillance yielded a comprehensive public health surveillance system — along with robust firewalls to protect confidentiality. Many surveillance personnel and advocates for people with HIV asserted that such registries should be used for epidemiologic purposes only — that data should go in but not come out.

Despite such deep resistance, pressure began to mount to ensure that surveillance data were used to serve public health ends. In 2007, a report from the Centers for Disease Control and Prevention (CDC) bluntly stated that "once the data are in hand it is the failure to use those data for public health purposes that must be justified."

New York City sought to pioneer new uses of its HIV registry. In 2005, city health commissioner Thomas Frieden proposed extending surveillance to the monitoring of viral loads and drug resistance, arguing that the data should provide a foundation for public health interventions targeting both patients and providers. "We know people are dying," he told the *New York Times*, "and we are prohibited by law from lifting a finger to try and help." He unsuccessfully sought to determine when people dropped out of care (indicated by a lack of regular tests for CD4 counts and viral loads) and then to reach out either to their health care providers or the patients themselves to help them regain access.

Strikingly, analyses of the debate over using surveillance data for clinical purposes focused heavily on social resistance grounded in classic arguments about violations of privacy and the protection of professional autonomy. Hardly noticed was the opposi-

tion from within the public health community. In New York, for example, it was state health officials who most ardently opposed new uses of data, even as they endorsed expanded surveillance for epidemiologic purposes. The reluctance was surprising, given the long history of using surveillance registries as a bridge between patients, medical providers, and health departments in the control of sexually transmitted diseases (STDs) and tuberculosis.

Advances in HIV treatment, however, began shifting the terms of the discussion, and in March 2011 the CDC convened a "Consultation on Monitoring the Use of Laboratory Data Reported to HIV Surveillance" to help craft recommendations for legitimate uses of confidential surveillance data. Central to this shift was the mounting evidence regarding the key role of linkage to care in controlling the epidemic's spread. It had long been established that, nationwide, approximately 25% of people with HIV infection don't know their HIV status. Moreover, of those who are aware that they're infected, 50% are not receiving regular HIV care.[2] Even in New York City, which provides an unusually strong package of benefits and treatment, less than half of the 76% of patients who continued to show evidence of care after an initial diagnosis managed to receive regular care (i.e., laboratory monitoring at least every 6 months) over the long term.[3]

All states but one now require laboratory-based reporting of CD4 cell counts to health departments, and all but four require reporting of viral loads. Nevertheless, only one state has begun to push information back out in ways intended to affect care.

The innovating state, Louisiana, could hardly boast about its record of STD control. In 2008–2009, it led the nation in rates of primary, secondary, and congenital syphilis and reported 17,000 people living with HIV, approximately 40% of whom were not in care.[4] But not all were lost to care entirely. Some 2500 persons with either untreated HIV or syphilis received other, unrelated medical services in the public hospital system in 2007. Yet their health care providers were unaware of their HIV or STD status.

To remedy this situation, the state Office of Public Health (OPH) created the Louisiana Public Health Information Exchange (LaPHIE). Today, when an "authorized medical provider" opens a patient's electronic medical record in the state hospital system, it triggers an automatic data query to OPH. LaPHIE determines whether the patient is an HIV-exposed infant or someone who tested positive for HIV but either was not informed of the results or hasn't received a CD4 test within the past 12 months.[5] In these instances, it returns an eye-catching "point-of-care message," alerting the caregiver that the patient is HIV-positive and not receiving care and providing an opportunity to offer appropriate services. At the March 2011 CDC consultation, Jane Herwehe of Louisiana State University presented data showing that this simple message, which merely triggers a conversation with the patient, resulted in approximately 75% of HIV-positive people returning to care during the pilot phase.

Characteristically, the state consulted extensively with members of the community, health care providers, and federal health officials on ethical matters before launching LaPHIE. Ironically, all this discussion masked the most substantial initial barrier the initiative faced: resistance from staff members of the Louisiana Office of HIV Surveillance. Their antagonism was grounded in both social and practical considerations. To build an HIV registry, the staff had become skilled at mining clinical records and other data registries. But though they regarded no data source as off-limits, officials resisted bringing those sensitive data together into a single, identified HIV record. Stigma remained a major reason for opposing measures that might put confidentiality at risk.

Technical considerations about when the data were "good enough" for clinical purposes have also been paramount. As one New York City official explained, "Matching is the single most dangerous part. It all falls down to how careful surveillance programs are with their 'fuzzies'" — laboratory reports that don't definitively belong to an individual in the registry.

Significantly, staff members who have long defended the walls around the HIV registry are reconsidering policies of containment and now believe it's time to open up HIV registries.[1] What pushed the matter to the tipping point were the data on retention in care. An analysis identifying "major gaps in continuity of care among persons newly diagnosed with HIV" convinced New York City's surveillance staff that the registry had the "capacity to monitor utilization of care, identify deficits, and evaluate progress in programs designed to facilitate retention in care."[3] Combining these data with the new understanding about the ways in which treatment reduces infectivity led

innovators to conclude that "The most important thing we can do is to actively link [those with HIV] into care." They have begun reconceiving of the registry as a kind of "universal" electronic medical record, a critical "resource for physicians" analogous to immunization registries or childhood wellness databases.[2]

At this point in the HIV epidemic — given the social context, the therapeutic prospects for individual patients, and the potential for interrupting transmission in the population — we must ask what is the greater mistake: opening up the registries, potentially giving infected people and clinicians more choice, or leaving those walls intact, recognizing that the data are imperfect and that some people don't want their information shared even with their own health care providers? We believe it is time to affirm that there is a public health duty to use surveillance data in new ways, for the sake of both populations and individuals — and then to begin the harder business of deciding when the data are adequate for us to start dismantling the Jericho-like walls from the inside out.

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