



“ **Should we eliminate all elevated levels of consent for HIV testing and embrace the simple consent model used to screen for most other chronic health issues?** ”

ON DECEMBER 1, 2006, the San Francisco AIDS Foundation hosted a World AIDS Day forum that brought together four nationally renowned expert panelists: **Timothy Mastro, MD**, Deputy Director for Science in the Division of HIV/AIDS Prevention at the Centers for Disease Control and Prevention; **Robert E. Fullilove, EdD**, Associate Dean for Community and Minority Affairs and Professor of Clinical Sociomedical Sciences at Columbia University’s Mailman School of Public Health; **Jennifer Kates, MA, MPA**, Vice President and Director of HIV Policy at the Kaiser Family Foundation; and our own **Judith Auerbach, PhD**, Deputy Executive Director for Science and Public Policy.

The following conversation is excerpted from panelists’ responses to a question about informed consent:

Timothy Mastro

I think we’ve tried to be clear relating to health-care settings—and again, our new recommendations are really for health-care settings—that it’s to offer HIV testing in a purely voluntary way with information, with knowledge, the ability to ask questions, and the right to decline it, and we think that is treating HIV like other important medical conditions for which there is an important screening test and there is very effective treatment. So we don’t think that special written informed consent is necessary for that kind of testing.

For testing *outside* of health-care settings, it’s sort of new terrain. Now

that’s often ... client initiated, where it’s sort of implicit that the person wants to get tested if they’re coming forward to get tested. But then there are other settings where you do go out and do outreach, ... reaching populations that often don’t access health care, and you’re going to do outreach testing—that’s a different issue. You’re going to go out and identify people, offer them the test, and then you do want a very explicit informed consent done for that testing.

Robert Fullilove

I think for me, I would really hope that—since this has all the appearances of an idea who’s time has come—we’ll really assess and evaluate very carefully whether or not we have hopeful results when we start to change the way we do this kind of testing in medical settings.... [M]y hope is that, as we break this out, we carefully examine whether or not we have any kind of impact that we thought we would have. I think we need to be guided, in other words, by evidence and by data that suggest we alter our approaches as we learn ... how to do this correctly.

Judith Auerbach

I think that’s a really important point, ... to try this in medical settings first and see how it goes and make sure that we’ve committed to the operations research to understand how well it is working and in what ways. That’s very important. I think some of the questions remain about what exactly that consent is going to look like, and

there are some examples from states that have been using these kinds of combination consent forms—written consent that says, “I’m consenting to the following tests.” ...So long as they’re offered the opportunity to ask questions, as Tim mentioned, and then offered counseling regardless of the results of the testing, that might be okay...

Timothy Mastro

Dealing with the clinical sector (who have been, I think, overwhelmingly supportive of the new recommendations), there’s a repeated, regular report that when they deal with their patients, their patients assume they’re being tested for HIV. They’ll present at a hospital or someplace when they are ill and [be asked], “Why didn’t you get tested before?” and they say, “What do you mean, doc, I was here six months ago. You guys must have tested me for HIV, right?” And why not? This happens at STD clinics as well as other clinical settings.

Jennifer Kates

We see this in our surveys. A minority of people—but a substantial minority—think they have just been tested because they saw their doctor and their doctor didn’t say anything to them, so they must have had an HIV test and been okay. Hopefully, if the guidelines are effective in being implemented, people can make that assumption and be right, as opposed to now when they’re probably wrong.

