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national news

Empowerment or danger?

Concerns about counseling and privacy divide community over HIV home test kit

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by Bob Roehr

ne day, perhaps soon, you may be able to walk into a drug store and lay down \$30 to purchase a home testing kit for HIV. Then, in the privacy of your home, you could prick your finger, place a drop of blood on a specially treated paper, and mail it to the lab. A few days later, you could call an 800 number to receive the results.

Direct Access Diagnostics, a subsidiary of the consumer health care products manufacturer Johnson & Johnson, has applied to the Food and Drug Administration for a license to sell such kits.

Johnson & Johnson president, Elliot Hillenson, said in testimony before the FDA that his company is "empowering people who choose to get testing and counseling in a setting that they are comfortable with."

Sean Strub is an AIDS activist and publisher of *POZ*, a slick new consumer-oriented AIDS magazine. He is also an

expert in marketing to the queer community. Direct Access is one of his clients, and the current issue of *POZ* contains a marketing survey on home test kits, paid for by Direct Access.

Strub is a "strong advocate" of expanded HIV testing. He sees this test as "an information tool." He opposed an earlier home test kit proposed by Burroughs-Wellcome "because that was really a pro"The potential for catastrophic impact on individuals using such a home test product far outweighs the intended advantages," said NALGHC coordinator Christopher Portelli. The group is concerned about the increased risk of suicides and inadequate counseling and referral as part of the proposed home test kit.

Perhaps the most vivid personal example was supplied by Hand Carde, a retired career naval officer living with AIDS. He said his three tours in Vietnam did not begin to compare with the tension he felt after learning he was HIV positive. "I was suicidal for three days," Carde said. He credits his survival in part to the counseling he received, and he doubts if it would have been nearly as effective over the phone.

Joining in opposition to home test kits were the National Gay and Lesbian Health Foundation and the National Association of People with AIDS.

> Most experts believe that anonymity and confidentiality are essential to the integrity of HIV testing. Current programs have achieved this by developing procedures which identify clients only by code numbers, not by name, and often by requiring the client to return in person to get test results. Direct Access would adapt those principles.

However, with telephone technology such as "caller ID," now available

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Strub got involved with Direct Access because, "I wanted to make sure that whatever expanded testing options were developed were separated from a predetermined course of treatment for someone who

is positive."

Tom Mosley supported the Direct Access license application in testimony before the FDA. Until recently, he managed the hot line and testing outreach for AIDS Project Los Angeles.

"My agenda is to have as many minority people as possible be diagnosed as early as possible, and home testing will do that," Mosley said. "Many minorities are distrustful of the medical system and will not be tested at all without the home kit."

Most experts agree that early knowledge of HIV status can be very important to limiting transmission of the virus to others. It can also lead to medical and lifestyle changes that can improve the length and quality of life for those already infected. They also agree that effective counseling is an important component of the testing process.

Where the experts begin to differ is over what constitutes effective counseling. Supporters of home testing maintain that telephone counseling is adequate, opponents disagree.

The National Alliance of Lesbian and Gay Health Clinics has announced its opposition to the Direct Access test kit. The Alliance represents 11 clinics across the country, from Boston to San Francisco.



to subscribers, and the fact that computers can track and record all 800 numbers, the potential exists for either commercial or government interests to easily match those captured numbers with tele-

phone subscriber lists, destroying the principle of anonymity.

This concerns care providers and civil libertarians because of the potential for intrusion and also for mis-identification by third parties, as the person making the call may not be the one in whose name the telephone service is registered.

It also increases the possibility of abuse or misuse by a third party. An employer, business partner or lover could take a blood sample, either surreptitiously or under false pretenses, turn it in, and get results—without even telling the person who has been tested. The current system relies upon the professional integrity of the medical community to take the blood sample and report test results only to the individual being tested.

Money is a large, unspoken factor underlying this debate over home test kits. The position of Direct Access Diagnostics is clear, they hope to make money by selling millions of kits each year.

But many AIDS service organizations also have a monetary stake in home testing. Testing and counseling are often a significant part of the services they now offer. And that means money—money raised from the private sector or in the form of government contracts. It is not surprising such groups would not favor having their clientele, and future dollars, diverted to a mail order provider.