What Is the Role of HIV Testing at Home?

Is home HIV testing feasible?

Home-access testing for HIV met with virtually unanimous opposition when it was first proposed. 1 Today, the Centers for Disease Control (CDC), leading clinicians, gay activists and AIDS advocates have all endorsed home access testing. 2 The barriers to home access testing have not been technical, as feasibility studies have demonstrated. 3 Home testing has been possible for more than a decade.

Actually, "home testing" is a little misleading: customers don't actually get on-the-spot results, the way they do with home test kits for glucose, cholesterol, blood pressure or pregnancy. The tests are really at-home "collection kits" to be purchased over the counter or through the mail. A test kit purchaser pricks his/her finger, puts a drop of blood on a piece of blotter paper, sends it off in the mail, then phones for results and counseling after a specified time.

In the spring of 1996, the Food and Drug Administration (FDA) approved the first HIV home collection test kit, Confide. The kit, sold by a subsidiary of Johnson & Johnson, was later withdrawn from the market. The FDA later licensed Home Access HIV-1 Test System, manufactured by Home Access Health Corporation of Chicago. This remains the only home collection kit approved for sale by the FDA, although a dozen other unapproved home test kits have been advertised for sale in newspapers and via the Internet. The FDA cautions against the use of these unapproved test kits, which have not been fully evaluated and "do not have a documented history of delivering dependable results." 4

How is it different?

It's an easy way for people to find out if they're HIV infected. Traditionally, getting tested for HIV has meant a trip to a doctor or clinic, getting blood drawn, then returning for results and counseling. The new home testing kits save two trips to the doctor or clinic. It also makes testing accessible for people who live in rural areas, or inner cities where clinics are scarce, too busy, or a long bus ride away.

Home testing also affords privacy. Some people are afraid to visit a clinic or doctor's office because they fear they will be recognized by neighbors, friends, or family. In a number of studies, at-risk individuals have expressed preference for anonymous systems of HIV testing. 5 Home testing has the potential for complete anonymity.

Offering another testing option is a step toward solving the national problem of inadequate HIV testing. An alarmingly high proportion of those at risk has not been tested for HIV. 6 Getting HIV test results becomes more and more important as means of bolstering the immune system and staving off

opportunistic infections improve. Pregnant women are being encouraged to take voluntary HIV tests in light of studies showing that treating HIV-infected pregnant women with zidovudine (AZT) can reduce the rate of maternal/fetal transmission of HIV by two-thirds. 7

Are the results reliable? private?

Millions of HIV antibody tests have been conducted using dried blood specimens. 8 Such testing is highly accurate when laboratory protocols for confirmatory testing and quality assurance mechanisms are followed. False positive results do occur in HIV testing, but at a very low rate. Some test kit blotters mailed to the lab may not have enough blood to test. In such situations, telephone counselors have been trained to advise customers when results are unclear or need further confirmation.

Each test comes with a unique identification number, which patients return to the lab with their blood samples. The lab never knows a name. When calling for results, patients identify themselves by this number alone.

Who will get tested at home?

Home access HIV testing may provide reassurance to the "worried well"-people for whom the risk of HIV infection may be quite remote, but are nevertheless seeking reassurance. If such individuals no longer rely on public sources of testing, resources may be freed up for more targeted interventions with those at highest risk. 9

Sales of home test kits have not been quite as robust as might have been expected from surveys in which people expressed their attitudes and intentions regarding home testing. In its first year, Home Access Health's sold 152,044 test kits; 148,039 people called to find out their results. The overall HIV seropositive rate was 0.9%. 10

Beyond the denial and psychological barriers to seeking testing, many may find the $30-40 retail cost for home test kits prohibitive. Home test kit companies are working with a variety of public health and community agencies, selling kits at wholesale prices so that home access testing can become part of various prevention outreach strategies.

What are the concerns?

One concern is the adequacy of counseling. At a doctor's office or clinic, test results are usually delivered in person. If a patient feels overwhelmed, or even suicidal, an expert is there to help. Companies selling home test kits make counselors available, but they will be miles away on the other end of a telephone. As one critic of home testing put it, "a 1-800 number can't hug you when you're crying." 11

Yet for some people, the remoteness and anonymity afforded by telephone counseling makes it easier to reveal painful feelings or embarrassing information. There is a long tradition with telephone counseling in crisis intervention and suicide prevention.

Telephone counseling must be compared to the actual experiences of current HIV testing. For many,

counseling is already inadequate or missing altogether. According to data from the National Health Interview Survey (NHIS), a third of those who were tested for HIV antibodies got their results by mail (16%) or telephone (17%). 12

About 2.5 million tests are performed annually at publicly funded test sites. In 1995, 25% of people who tested positive and 33% who tested negative failed to return for their results. 13 In contrast, 97.4% of buyers of the home test kit called for test results. 10

Another concern is potential abuse of home test kits. Some fear that employers, family members or health providers could send someone's blood sample to be tested without the person's knowledge. Laws already exist against testing without consent and discrimination on the basis of HIV status. These statutes need to be enforced; new legal protections may be needed once there is more experience with home test kits.

What are the limitations?

A positive HIV test result does not guarantee access to needed care. As the National Commission on AIDS wrote, "for many impoverished individuals gaining entry into a health care and social service system by means of a ticket stamped `HIV positive' is still a cruel hoax." 14 Nevertheless, this is no reason to discourage people from seeking testing. "The lack of good medical and social services for people with HIV infection is an argument for increasing those services, not denying people access to personal medical information." 15

HIV testing is not an end in itself. A comprehensive HIV prevention strategy uses multiple elements to protect as many people at risk of HIV infection as possible. The real challenge is to ensure that wherever people are tested they have access to follow-up counseling and care. If they are HIV positive they should receive care to stay healthy, and if they are HIV negative they should receive support to stay negative.

Says who?

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