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INFORMED CONSENT FOR AIDS TESTING

House Bill 5189 as enrolled
Second Analysis (1-23-89)

Sponsor: Rep. Teola Hunter
House Committee: Public Health
Senate Committee: Health Policy

THE APPARENT PROBLEM:

There currently is no known vaccine or cure for Acquired Immunodeficiency Syndrome (AIDS), the final, fatal stage of infection from human immunodeficiency virus (HIV). Someone may be infected with HIV for months or even years without any overt symptoms. But once infected, one can never get rid of the virus and one can transmit it to others (in this country most commonly through sexual intercourse with an infected partner and through sharing infected drug injection equipment, such as needles). Because of this long, asymptomatic "incubation" period and because there is no vaccine or cure, much of the current effort to reduce the spread of AIDS has centered on education of the public so that individuals can modify their behavior to reduce their — and others' — risk of exposure to HIV. However, although there are good reasons for people to wish to learn their HIV status, there also are strong disincentives to being tested if the test results are not adequately protected. Fears about the disease, coupled with the absence of any known cure (and the social stigmatization of some of the behavior involved in the transmission of the virus), have sometimes given rise to abusive and even illegal action against HIV-infected individuals. The bill, one of six legislative recommendations by the AIDS Subcommittee to the House of Representatives' Public Health Committee, addresses this problem.

THE CONTENT OF THE BILL:

The bill would amend the Public Health Code to require, with certain exceptions:

- written informed consent for HIV testing;
- counseling both before and after an HIV test;
- the availability of anonymous HIV-testing (and, where test results are positive, contact tracing);
- the confidentiality of certain kinds of information on communicable diseases or infections (including HIV infection and AIDS).

More specifically, the bill would add two new sections to Part 51 ("General Provisions") of Article 5 ("Prevention and Control of Diseases, Infections, and Disabilities") of the Public Health Code. One section would require the confidentiality of certain information ("all reports, records, and data pertaining to testing, care, treatment, reporting and research") on communicable diseases or infections (including the newly-defined class of "serious" communicable diseases or infections); it also would detail the circumstances under which such confidential information could be released. (Note: "Serious communicable disease or infection" would be defined in Senate Bill 1041 to include "HIV infection, acquired immunodeficiency syndrome, acquired immunodeficiency syndrome related complex, venereal disease, and tuberculosis.") The other new section would detail requirements (and exceptions to these requirements) for HIV testing, including written informed consent, pre- and post-test counseling, and the availability of anonymous testing.

General Confidentiality Provisions.

Confidentiality. Under the bill, all reports, records, and data regarding the testing, care, treatment, reporting, and research on communicable diseases or infections (including "serious" communicable diseases or infections) would be confidential. The test results (and the fact that such a test was ordered) would be "privileged information" under the physician-patient privilege section of the Revised Judicature Act, and could not be disclosed by physicians except as allowed by that act or by other laws. Information on communicable diseases or infections that was released to a legislative body could not identify any specific person who was tested (or who was being treated) for such a disease or infection.

Exceptions. This confidential information could be released under the following circumstances:

- if required by the Child Protection Law (which says that for purposes of the act's reporting requirements, the presence of venereal disease in a child less than 12 years old is "reasonable cause to suspect child abuse and neglect");
- if required by a court order (see below);
- upon written authorization by the subject in question;
- if allowed under new provisions detailed in House Bills 4103, 4008, and 5026 (which deal with contact tracing, "high risk" crimes, and recalcitrant carriers of communicable diseases or infections, respectively).

Physicians and public health officers also could give such confidential information to other health care providers, to school personnel, and to known "contacts" (the bill does not define "contact") of people with communicable diseases or infections under the following conditions:

- to health care providers (including the state and local public health departments), if they needed the information to diagnose and treat patients, to protect people's health, or to prevent the spread of the disease or infection;
- to school employees or to known "contacts" of people with communicable diseases or infections, if the physician or local public health officer decided that disclosure of such information was necessary to prevent "a reasonably foreseeable risk of further transmission" of the disease or infection. (However, although physicians would be allowed to provide this information to "contacts," they would not be required to do so.)

Confidential information given to health care providers, school personnel, or "contacts" under these circumstances could not include information that identified a specific subject unless identification was authorized in writing by the subject in question, or the physician or health officer disclosing the information decided that such identification

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was "reasonably necessary to prevent a foreseeable risk of transmission" of the communicable disease or infection. A physician or health officer who released confidential information in accordance with these provisions would be immune from civil or criminal liability or administrative penalties (including licensure sanctions) for releasing the information.

Court-ordered disclosure. Before ordering the release of confidential information concerning a communicable disease or infection, the court would be required to find that there was no other effective way of getting the information and that the potential harm to the patient in question was outweighed by the public interest and need for disclosure. When ordering the release of such confidential information, the court would be required to limit the amount of information and the extent of disclosure to that information necessary to fulfill the objective of the order and to the people whose need for the information formed the basis of the order.

Penalties for breach of confidentiality. The bill would establish three categories of penalties for unlawfully revealing information protected under the bill, based on whether or not the violator worked for the government and whether or not the case involved a serious communicable disease (that is, AIDS, ARC, HIV infection, VD, or TB).

(1) For communicable diseases other than serious communicable diseases, violators would be guilty of a misdemeanor punishable by up to 90 days in jail and a fine of up to $500.

(2) For serious communicable diseases or infections, people in the private sector (except for those under contract to governmental units) who violated the bill's confidentiality provisions would be liable to civil action for actual damages or $1,000, whichever was greater. Employers of such violators also would be liable to the same degree, unless they had taken reasonable precautions to prevent such unlawful disclosure by their employees.

(3) Government employees (including those under contract to a governmental entity) who unlawfully disclosed confidential information about someone with a serious communicable disease or infection would be guilty of a felony punishable by up to three years in prison and a fine of up to $5,000.

HIV Testing.

Informed Consent. Except under certain emergency circumstances, a physician (or someone delegated by the physician), before ordering an HIV test, would be required to get the proposed test subject's written informed consent. Under the bill, "informed consent" would consist of a "writing" signed by the proposed test subject (or his or her legally authorized representative) which included, minimally, (a) an explanation of the test (including its purpose, its potential uses and limitations, and the meaning of test results); (b) an explanation of the subject's rights (including the right to change his or her mind about having the test done, the right to have the test results kept confidential, and the right to be tested anonymously); and (c) a description of people to whom the test results may be given. Within 120 days of the effective date of the bill, to get a patient's informed consent for HIV testing, physicians would be required to use an information form that would be developed by the DPH. (Within 100 days of the effective date of the bill, the state's two medical boards would be required to inform their members in writing of the bill's requirements and of the availability — from the boards and from the health department — of the required form.)

A patient who signed a "writing" as defined by the bill could not later sue his or her physician for failure to obtain informed consent. Further, when a test subject was given an information form developed by the DPH, he or she would be required to sign a form to that effect, which then would be included in his or her medical record.

Public Health Information Form. Within 90 days of the effective date of the bill, the DPH would be required to develop and have ready for distribution an information form on HIV testing which included a standard informed consent form. Physicians would be able request free copies of the information form either directly from the DPH or through their medical boards (the Board of Medicine for allopaths, the Board of Osteopathic Medicine and Surgery for osteopaths). The DPH would be required to give free copies of the form to the two medical boards for distribution to their members and, upon request, directly both to physicians and to public or private schools, colleges, and universities. Others could get copies of the form at cost from the DPH by written request.

The form would have to be available both in clear, nontechnical English and in Spanish. In addition to the standard consent form containing information about the test subject's rights, the information form also would have to include information on the purpose and nature of the test, the consequences of taking and not taking the test, the meaning of the test results, and any other information the DPH believed necessary or relevant.

Anonymous testing. When someone went to be tested at a site approved by the Department of Public Health, he or she would be able to request that the test be done anonymously, giving consent to the testing through a coded system which would not link his or her identity with either the test results or the request for the test. If someone requested anonymous HIV testing, the test would have to be done anonymously or under the condition that the test subject not be identified. However, if the test indicated that the subject was HIV infected, the testing site staff would be required to notify the subject's partners "in the same manner" as local health departments would required to do by House Bill 4103 (which would require local health departments to "confidentially, privately, and in a discreet manner contact each individual identified as a sexual or hypodermic needle-sharing or drug-sharing partner regarding the individual's possible exposure to HIV").

Mandatory counseling. Except under certain emergency circumstances, physicians who ordered HIV tests or health facilities that performed such tests would be required to provide the test subject with appropriate counseling both before and after the test was done.

Exceptions to Prior Written Informed Consent and Mandatory Counseling. Written informed consent for HIV testing and counseling would not be required if:

(a) the test were done as part of research in which the researcher did not know the test subject's identity and the subject was not given the test results;

(b) the test was done as part of a standard protocol developed by a health facility for patients being prepared for an "incisive or invasive" surgical procedure;

(c) the test was done after a health professional (or other health facility employee) was exposed (through the skin, a mucous membrane, or an open wound) to the blood or

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other body fluids of a patient in a health facility that informed patients in writing, as part of its admission procedures, that HIV testing would be performed without written informed consent whenever this kind of exposure to health personnel occurred;

(d) the test *subject was unable to give informed consent* to the test or understand information about HIV testing and his or her legally authorized representative was not readily available.

However, if the test results of a surgical patient or an emergency patient unable to give informed consent indicated that the patient was HIV infected, the health facility would be required to tell the patient of the positive test results and provide appropriate counseling regarding HIV infection, AIDS, and ARC.

Tie-bars. The bill is tie-barred to House Bill 4008, House Bill 4103, House Bill 5026, and Senate Bill 1041, which deal with "high risk" crimes, contact tracing, recalcitrant HIV carriers, and responsibility for expense of care respectively.

MCL 333.5131 and 333.5133

FISCAL IMPLICATIONS:

The House Fiscal Agency estimates that it will cost the DPH $337,500 to develop, print, and distribute the informational pamphlet required by the bill. Additional unknown costs will be incurred by local health departments, if they do contact tracing under the "duty to warn" section of the bill. (12-5-88)

ARGUMENTS:

For:

The bill would encourage testing for HIV infection by guaranteeing that all such testing could be done only with the written informed consent of the test subject and by allowing most people the option of being tested anonymously. The confidentiality provisions are backed by strong penalties for breach of confidentiality, with the exceptions being only those necessary for specific (and in most cases, public health) "need to know" cases.

Against:

While informed consent for HIV testing and confidentiality of test results are highly desirable, the numerous exceptions to confidentiality must inevitably result in "leaks" and in the kind of public "backlash" that HIV-infected people rightly fear. And breach of confidentiality is not rare. A survey conducted by the Association of State and Territorial Health Officials (ASTHO) reported in June, 1988, that there had been at least 75 cases of AIDS-related breaches of confidentiality (usually involving release of a patient's name and diagnosis by hospital staff members — both medical professionals and clerical staff — either to an employer or to the media) and 233 acts of AIDS-related discrimination (though the New York City Commission on Human Rights alone reported receiving 614 AIDS-related discrimination cases between January 1986 and June 1988, so obviously there were more than 75 cases nation-wide and, perhaps, a reluctance to report such incidents). Breaches of confidentiality often disrupted the person's family or living situation and sometimes led to the loss of a job or an inability to get medical care. And according to one newspaper report, a woman's family even asked her not to use the family name once they found out that she was HIV infected. ASTHO recommended that HIV antibody test results be released only with the consent of the person tested and that states adopt laws barring release of name-linked information under subpoena or court order. This seems the only way to truly guarantee the confidentiality of test results (and thereby truly encourage widespread HIV testing).

Response: The ASTHO report also said that most of the AIDS-related discrimination cases followed a voluntary disclosure, which means breach of confidentiality wasn't even involved. The report also did recommend that HIV testing be preceded by counseling and informed consent (written, informed consent is required by the bill), that testing counselors should tell people about the possible repercussions of revealing their HIV status, and that health care providers and agencies develop policies to assure confidentiality.

Against:

The restrictions on anonymous testing at health department-approved sites virtually eliminate the availability of anonymous testing, which, in turn, will discourage people from getting tested. The bill restricts anonymous testing at approved sites in two ways: In the first place, even if people do request anonymous testing at a health department-approved site, the site staff — and not the potential test subject — are the ones who decide whether this request is to be honored or whether the test will be done "under the condition that the test subject not be identified." (It is not clear what this means, or who it is that is not to identify the test subject.) But apart from the fact that staff need not honor a request for anonymous testing, they have a positive disincentive for allowing such testing because they are required to do partner notification in cases where people test positive for HIV. Unless staff can identify who tests positive, they can hardly identify that person's partners, which means that anonymous testing will not be readily available. The only way to guarantee the availability of anonymous testing is to allow *truly anonymous testing, with the identify of the test subject* known only to that person.