ABSTRACT

Objective: To enhance HIV surveillance within a non-nominal provincial testing system.

Methods: Confirmatory HIV tests from a provincial laboratory were analyzed during 1995 and 1996. Enhancements included elimination of repeat positive tests for the same individual using automated matching of non-nominal identifiers and nurse call-back of health care providers, completion of missing information through call-back and connection of providers with resources for patient care.

Results: Forty-seven percent of 2,683 reactive HIV tests were identified as duplicates for the same individual, meaning that 1,401 people tested positive for the first time. From laboratory test data to enhanced unduplicated data after call-back, the proportion of tests for which risk and ethnic information was unknown dropped from 37% to 11% and from 64% to 18% respectively ($p < 0.0001$).

Conclusions: Enhanced non-nominal surveillance for HIV is a practical means of marrying the needs of public health for epidemiological information and the rights of patients to privacy.

ABRÉGÉ

Objectif: Améliorer la surveillance du VIH à l'intérieur d'un système de dépistage provincial non-nominal.

Méthodes : Les tests de confirmation du VIH provenant du laboratoire provincial furent analysés utilisant un système de surveillance amélioré en 1995 et 1996. Les doublons furent éliminés à l'aide d'un système informatique jumelant les données non-nominales et d'une infirmière appelant les travailleurs de la santé. Lors des appels, l'infirmière recueillait certains renseignements manquants et informait quant aux ressources disponibles pour les patients.

Résultats : Quarante-sept pour cent des 2 683 tests positifs au VIH furent identifiés comme doublons provenant de mêmes individus. Des données de laboratoires brutes aux données améliorées, la proportion des tests pour lesquels les facteurs de risque et l'origine ethnique étaient inconnus a baissé de 37 % à 11 % et de 64 % à 18 % respectivement ($p < 0,0001$).

Conclusion : La surveillance non-nominale du VIH est un moyen pratique de répondre aux besoins de données épidémiologiques de la santé publique et du respect des droits à la confidentialité des individus.

Non-Nominal HIV Surveillance: Preserving Privacy While Tracking an Epidemic

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In many jurisdictions, the use of population-based testing data to obtain an accurate view of the HIV epidemic is hampered by concerns over confidentiality. Omission of unique patient identifiers from testing requisitions leads to difficulty with identifying duplicated tests and with obtaining missing risk and demographic data.

Anonymous systems, where only the client is able to link herself to a test result, assure confidentiality but limit epidemiological use of testing data. Nominal testing systems (requiring name) partially solve this problem but do not meet everyone's expectations for confidentiality and may change the acceptance of testing by certain groups.¹ In British Columbia, HIV testing is performed on a non-nominal basis. Names are not required but initials and birth date are requested and used on test requisitions. Rather than modifying a system which has been accepted by physicians and community in B.C., we sought to improve HIV surveillance by making better use of existing non-nominal data. We hypothesized that in addition to eliminating duplicate counting, proposed enhancements would lead to more complete ascertainment of risk and demographic data for those newly diagnosed with HIV.

METHODS

Development of non-nominal surveillance

Although AIDS has been a reportable disease in British Columbia since January 31, 1983, HIV infection is not reportable by physicians. Non-nominal HIV testing in British Columbia began on October 7, 1985. Ninety-seven percent of enzyme immunoassay testing and all confirmatory Western Blot testing is performed at the Provincial Laboratory.

In 1994, a new HIV testing requisition was developed which requests that providers enter information on a patient's birth date, gender, risk behaviour, ethnicity, previous HIV serology, whether the test was performed for prenatal screening and the patient's initials (Figure 1).

Information from requisitions was recorded in a laboratory testing data base maintained in MUMPS — the Massachusetts General Hospital Utility Multi-Programming System (Micronetics Design Corp., Rockville, Maryland). From January 1, 1995, through December 31, 1996, these data were downloaded to a case surveillance data base system. The system employs a straightforward dBase IIIP (Borland International Inc., Scott City, CA) file format with all programs written in Clipper (Nantucket Corp., Los Angeles, CA).

Elimination of duplicate tests

Two methods of duplicate removal were applied in sequence to all records. Records of reactive HIV tests from 1995 and 1996 were first matched electronically for three initials, gender and date of birth against all prior-dated positive test results from 1985-1996. During an evaluation period, putative matches were validated by checking

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concordance of ethnicity, risk factor and any nominal information provided on requisitions. Health providers were also asked to verify the match.

A nurse performed follow-up on each new HIV positive test with the health care provider. In this consultation, the nurse did not seek to learn the name of the patient but used telephone or written communication to obtain or confirm risk and demographic data including the city or town in which the testing was performed and symptoms at diagnosis. S/he would also check to see if the provider was aware of a previous positive test for HIV for the patient. During an evaluation period, providers' reports of prior positive tests were validated by comparison with laboratory testing records and confirmation of hard copy documentation by physicians.

Once the above methods of duplicate recognition were evaluated and validated, both were employed to eliminate duplicate positive tests for the same individual from the data base and the nurse no longer called providers regarding tests for which a previous positive result was identified by either method. Individual patient-based files were closed once follow-up with the health care provider had been completed.

Infants with a positive HIV antibody test were not considered infected unless the test result was obtained at greater than 18 months of age or HIV was directly detectable on two consecutive occasions using PCR, viral culture or p24 antigen.

Other aspects of health care provider follow-up

The interaction with the provider offered an opportunity to share information about care and treatment resources for HIV/AIDS and to help keep physicians aware of changes in treatment recommendations. For example, clinicians were made aware of treatment options and protocols for new HIV seroconverters and for pregnant women diagnosed with HIV. During the follow-up, the need for partner notification was emphasized.

Statistical methods

Databases produced as above consisted of non-nominal records for first known positive tests for individuals (newly docu-

PROVINCIAL LABORATORY
B.C. CENTRE FOR DISEASE CONTROL SOCIETY

HIV SEROLOGY
(HUMAN IMMUNODEFICIENCY VIRUS)

HIV LABORATORY USE ONLY

PATIENT NAME OR INITIALS: FIRST, MIDDLE, LAST, SEX (M ☐ F ☐)

DATE SPECIMEN COLLECTED: YR. MO. DAY, PATIENT'S CITY RESIDENCE, DATE OF BIRTH: YR. MO. DAY

DOCTOR'S PHONE No. _____ SUBMITTER'S REF. No. _____

DOCTOR'S MSC No. _____

DOCTOR OR HOSPITAL _____

STAMP, PRINT OR TYPE FULL POSTAL ADDRESS IN BOX

COPY OF REPORT TO DOCTOR'S MSC No. 1. _____ 2. _____ 3. _____

ETHNICITY:

- ☐ WHITE
- ☐ ASIAN
- ☐ NATIVE INDIAN
- ☐ SOUTH ASIAN
- ☐ INUIT
- ☐ METIS
- ☐ BLACK
- ☐ HISPANIC
- ☐ OTHER (Specify) _____

RISK FACTORS:

- ☐ HOMOSEXUAL/BISexual
- ☐ INJECTION DRUG USER
- ☐ HETEROSEXUALLY ACTIVE
- ☐ HEMOPHILIC
- ☐ PROSTITUTE
- ☐ RECEIVED BLOOD OR BLOOD PRODUCTS
- ☐ OTHER (Specify) _____

THIS TEST IS PART OF A:

- ☐ PRENATAL ASSESSMENT
- ☐ VISA REQUIREMENT

PREVIOUS HIV SEROLOGY? ☐ YES ☐ NO

IF YES, RESULT _____

IF PREVIOUSLY TESTED POSITIVE, IN WHICH PROVINCE WAS FIRST POSITIVE TEST RECORDED? _____

TESTS REQUESTED

- ☐ HIV
- ☐ HIV + HTLV
- ☐ HTLV

HLTH 1812 Rev. 98/01 C-27/95/02

INSTRUCTIONS

1. Submit a full tube of blood in B.C. special Vacutainer (outfit code AT). If the test request is HTLV serology and not HIV, be sure this is clearly marked on the requisition.
2. STAT tests for HIV antibodies are routinely available for organ and tissue donors. Any other requests for STAT testing must be authorized by medical staff of the Provincial Laboratory (telephone (604) 661-7033) or the virology laboratory supervisor (telephone (604) 660-6045).
3. Required information:
 - (a) Patient name or initials
 - (b) Sex
 - (c) Date of birth
 - (d) Physician name and address and MSC billing number
 - (e) Risk factor
 Tests may not be performed unless all above information is included. Incomplete requisitions may be returned to the physician for additional information.

MR-1280

Figure 1. HIV Test Requisition from the BC Centre for Disease Control

mented HIV infections). Descriptive analyses, frequency tables, cross tabulations and contingency table analyses were produced using Statistical Analysis Software (Cary, NC) and Epi Info (USD Inc., Stone Mountain, GA). Chi-square and Fisher exact tests were employed for tests of significance for independent proportions and McNemar's test was employed for tests of paired proportions. The level of significance was set at $\alpha=0.05$.

RESULTS

During 1995 and 1996, a total of 280,611 HIV tests were performed through all laboratories in the province, of which 2,683 were reactive. "Reason for

test" is not requested on laboratory requisitions, but 40,438 tests were received indicating prenatal screening as an indication and it is likely that the majority of tests are submitted for screening rather than diagnostic purposes.

Identifying new positive tests

Contact with physicians was most often accomplished by one or two telephone calls but in some instances, a request for information was mailed.

Of 466 records of a reactive test for the pilot period January through May, 1995, 75 were identified as possible duplicate tests using the computerized algorithm. When potential duplicate pairs were compared for concordance of other variables

TABLE I
Sources of Data on HIV (January 1, 1995 - December 31, 1996)

	Laboratory Test Data n=2,683		Enhanced Unduplicated Data (Individuals) n=1,401	
Female (%)	666	(24.8%)	323	(23.1%)
Male (%)	1,916	(71.4%)	1,070	(76.4%)
Gender Unknown (%)	101	(3.8%)	8	(0.6%)
MSM	457	(17.0%)	342	(24.4%)
IDU	857	(31.9%)	577	(41.2%)
MSM/IDU	45	(1.7%)	52	(3.7%)
Sex Trade	11	(0.4%)	1	(0.1%)
Sex Trade/IDU	58	(2.2%)	79	(5.6%)
Heterosexual Contact	174	(6.5%)	149	(10.6%)
Other Risk	60	(2.2%)	49	(3.5%)
Risk Unknown	1,021	(38.1%)	152	(10.9%)
Black	28	(1.0%)	31	(2.2%)
Hispanic	20	(0.7%)	36	(2.6%)
Native	187	(7.0%)	207	(14.8%)
South Asian	16	(0.6%)	27	(1.9%)
White	697	(26.0%)	798	(56.9%)
Asian	29	(1.1%)	32	(2.3%)
Other			21	(1.5%)
Ethnicity Unknown	1,706	(63.6%)	249	(17.8%)
Age Group (years)				
<15	35	(1.3%)	6	(0.4%)
15-19	32	(1.2%)	15	(1.1%)
20-29	649	(24.2%)	342	(24.4%)
30-39	1,197	(44.6%)	629	(44.9%)
40-49	539	(20.1%)	302	(21.5%)
50+	221	(8.2%)	99	(7.1%)
Unknown	10	(0.4%)	8	(0.6%)

MSM - men who have sex with men
IDU - injection drug user

provided on requisitions, and discussed with providers, all were confirmed as duplicates.

A sample of 23 records of a positive test where a previous reactive test had been indicated by the health care provider were studied. Twenty-two of these cases were subsequently verified as HIV positive from laboratory test results and provider records.

Both automated match and provider identification of duplicate tests were subsequently applied to the remainder of the database. The enhanced data on first time positive tests for 1995-1996 were compared with unrevised laboratory data from the same year (Table I).

Description of those testing positive for the first time

There were 1,401 individuals with a newly documented HIV infection (a 47% reduction due to elimination of duplicate tests for the same individual) (Table I). In comparing laboratory testing data with unduplicated enhanced data, the propor-

tion of tests for which risk information was unknown dropped from 37% to 11%, and for which ethnic information was unknown dropped from 64% to 18% after follow-up with the health care provider. (Providers frequently remained uncertain of patient ethnicity.) Improvements in information on risk and ethnicity for charts appearing both in laboratory testing data and the enhanced unduplicated data set were significant (both $p < 0.0001$) by the McNemar test.

At the time of testing, 55% of the subjects were asymptomatic, 18% had symptoms of later-stage disease and 4% had symptoms compatible with seroconversion described.² Overall, 66% of all tests from 1995 and 1996 came from the city of Vancouver but reactive tests were recorded from all regions of British Columbia. Of 713 individuals with a first reactive test in 1996, 55% were tested by general practitioners, 15% by general hospitals, 15% by outreach nurses and physicians working with the British Columbia Centre for

Disease Control, 3% by the Downtown Community Health Clinic (Vancouver), 2% by health units and 10% by an ongoing cohort study of injection drug users (data not tabulated).

DISCUSSION

By identifying duplicate tests and supplying missing information, the described non-nominal surveillance system gives a clearer picture of newly documented HIV infections than was possible through unmodified laboratory surveillance. It provided the first clear indication of a burgeoning epidemic of HIV among injection drug users in British Columbia and demonstrated that native British Columbians are at higher risk for HIV than some other ethnic groups within the province.^{3,4} An identified duplication rate of 47%, though apparently high, is expected if the majority of providers are complying with guidelines and submitting a second specimen to confirm all new diagnoses.

Other jurisdictions have taken similar approaches to HIV surveillance without requiring nominal reporting. In the state of Victoria, Australia, a system has been employed which utilizes information from test requisitions, uses a code rather than a full client name, involves some call-backs to health providers and makes efforts to eliminate duplicates.⁵ In this project, we have made efforts to validate the means by which such duplicates are removed.

In Ontario, duplicate tests have been eliminated using a computerized algorithm which employs probabilistic rather than exact matching of selected fields.⁶ Follow-up questionnaires are sent to physicians with incomplete requisitions. This may be a better alternative in jurisdictions with larger numbers of tests. Our experience has shown verbal contact with *each* health care provider to be a useful enhancement. It provides a means of identifying duplicate records which would not be apparent from examination of birth dates, gender or initials. This process has resulted in enhancement of duplicate reduction from 22% to 47%.

The states of Maryland and Texas employed a compound "non-name"

unique identifier derived from a portion of the social security number, date of birth and codes for ethnicity and gender.⁷ Because such a code was missing from a large proportion of results, there was a high rate of incomplete case reporting. The use of a simpler non-nominal code (initials and date of birth) combined with nurse call-back to assure more complete reporting may be more readily applied where acceptable to community.

Our described system is subject to a number of limitations:

1. There is a self selection of those presenting for HIV testing. While 25% of Canadian men and 28% of Canadian women between the ages of 20 and 34 report having been tested for HIV on telephone interview,⁸ these data must continue to be supplemented by cohort and cross-sectional prevalence studies in various settings.
2. Findings may be *influenced* by the presence of cohort studies. The Vancouver Injection Drug User Study accounted for 10% of all newly identified positive tests for HIV in BC during 1996.⁴
3. There is no current process for eliminating duplicate positive tests across jurisdictions in Canada. Development of similar systems in other jurisdictions may allow this in the future.
4. More detailed data on the risks of heterosexual partners has yet to be collected. In Australia, 17% of males and 65% of females who have acquired HIV through heterosexual coupling report high risk partners.⁹
5. Generalizability may be limited as not all jurisdictions have all confirmatory HIV tests conducted at one laboratory or two thirds of positive tests coming from one urban area.

6. Nurse call-back requires one-half of the services of a full-time nurse on an ongoing basis to maintain the quality of data. This is labour intensive for units with the responsibility of reporting on many diseases.

Our HIV surveillance system is currently made possible through free access to testing and centralized confirmatory testing in the Province of British Columbia. Institution of a user pay system and greater involvement of commercial laboratories have been shown to reduce the volume and quality of data in other settings.¹⁰ Widespread adoption of home HIV collection and/or home testing,¹¹ unless accompanied by well-monitored non-nominal reporting of positive results could also dilute the value of data generated by such systems.

Communities affected by HIV have been justifiably sensitive about confidentiality. The described approach to non-nominal surveillance addresses this concern but produces most of the results one might expect of a nominal system. The above limitations considered, a strength of this method is a broader scope than is possible using other prospective epidemiologic designs. The opportunity to discuss with providers the critical issues in managing the newly diagnosed HIV-positive patient and assuring that they have received and communicated the result to the patient are significant added benefits. Enhanced, non-nominal surveillance for HIV is a practical means of marrying the needs of public health for epidemiological information and the rights of patients to privacy.

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