Anonymous HIV Testing: Evidence Review and Environmental Scan

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I. INTRODUCTION AND PURPOSE

HIV has been a reportable disease in British Columbia since 2003; however, communicable disease regulations require that clients seeking HIV testing be given the option of suppressing their name and address when a positive result is reported to public health. This non-nominal testing option has thereby afforded additional protection of privacy for those testing for HIV. Although use of non-nominal testing in BC has declined over time, 13% of those newly diagnosed with HIV in 2010 tested non-nominally. Pervasive stigma associated with HIV testing or infection is likely a driving force behind privacy/confidentiality-related concerns in BC and continues to pose a barrier to accessing HIV testing across multiple populations.

Numerous challenges in the implementation of non-nominal testing have been raised by public health and community stakeholders. In light of these challenges and the ongoing need to provide privacy-related protections, the BC Communicable Disease Policy Committee has agreed to explore a pilot anonymous HIV testing project in BC. To set the background for such a proposal, this paper outlines: 1) the measured impact of anonymous testing in places where it has been implemented (with particular focus on the experience in the US and Canada), and 2) best practices in the offer of anonymous testing in a subset of Canadian provinces.

II. DEFINITIONS

Confidential HIV testing: Provider-patient confidentiality is a fundamental principle of health care in BC, and this applies to all laboratory tests. For the purpose of this paper, “confidential HIV testing” refers to additional confidentiality protections that are applied to HIV testing in particular, such as non-nominal testing.

Anonymous testing is defined as testing in which results can be linked to the person testing by a code known only to the patient/client. Thus, while the caregiver who ordered the test and/or provided pre-test counseling can visually identify the person, the result of the test cannot be linked to that person; the person being tested must provide the code in order to retrieve the result. Anonymous HIV testing is available in all Canadian provinces, with the exception of BC and Prince Edward Island, and in forty US states. It has been explored in other jurisdictions globally, but with wide variation in execution of the anonymous test option at the level of clinic or provider.

Non-Nominal Testing: The HIV test is ordered using codes/initials/aliases and contact information for the client may be provided to the tester. The person ordering the HIV test may or may not know the true identity of the person being tested. The result of the test is entered in the client record at the site of testing however the name and address of an individual with a positive result is not reported to public health. At clinics where available, this option is typically applied to all tests performed for the client (e.g., STIs, viral hepatitis, HIV). In BC, the ability to test under initials or a pseudonym is not prescribed by the CD regulation; rather this is a matter of practice/policy of the provider or site ordering the test. This is a practice that is currently available at clinics which send specimens for testing directly to the PHSA laboratory (i.e. Lower Mainland sites). Non-nominal testing is available in all provinces and territories in Canada, although there is likely variation in how this is implemented.

Non-Nominal Reporting: A client who has a HIV test either ordered using codes/initials/aliases or full names and receives a positive result does not have their name,
address or contact information reported to public health. The result of the test would be entered in the client record at the site of testing. In BC, this option is described in the Communicable Disease Regulation.

**Nominal testing** within this summary is defined as testing conducted, requested, and reported using the client’s full name, address, and contact information (e.g., as occurs when using a Care Card to access testing). In the literature this is often referred to as “confidential” testing; however, given that confidentiality is a fundamental principle which applies to all HIV tests, the term is replaced with “nominal” in this document to distinguish from non-nominal and anonymous options.

### III. EVIDENCE OF THE IMPACT OF ANONYMOUS TESTING

#### Methods and scope of review

**Literature:** Published and gray literature concerning the evaluation of anonymous HIV testing were identified through PubMed search, Google search, governmental websites (especially PHAC, US CDC, Canadian provinces), and by reviewing the citation lists of the resulting reports. For the purposes of this review, reports were limited to those from the US, Canada, and Europe. No limits were applied with respect to date, but greater emphasis was given to more recent publications.

**Environmental scan:** Counterparts working in the HIV field in Ontario, Quebec, Alberta, and Nova Scotia were contacted by email or phone and asked to describe the anonymous HIV testing programs in their provinces. Evaluation data or reports were requested from each jurisdiction, as were policies, procedures, and other best practice documents which explain how anonymous testing is operationalized in other provinces in Canada.

#### Results

1. **Trends in the use of anonymous testing over time**

**Canada:** Among the four provinces surveyed, the number of anonymous HIV tests conducted over time shows discrepant patterns and likely corresponds to provincial or institutional policies surrounding the availability of anonymous testing. In Ontario, where anonymous testing is delivered through multiple designated sites across the province, use of anonymous testing appears to have remained steady or even slightly increased: in 1992-93, when anonymous testing was first introduced, ~4% of the ~250K HIV tests in the province were administered anonymously (versus 20% non-nominal and 71% nominal). The volume of anonymous tests fluctuated over the following decade, with a slight decrease from 1998 to 2002 (constituting ~3% of all HIV tests in 2002); however, in 2007, 11% of the ~410K HIV tests in the province were anonymous (versus 11% non-nominal and 79% nominal). Much of this increase can be explained by the expansion of designated anonymous test sites, from 26 to 50 in 2007.

Likewise, in Nova Scotia, where anonymous testing is delivered through three designated sites, provincial volumes of anonymous HIV testing have remained constant, averaging ~500 tests annually in 2000-09 and ranging from ~420 (in 2004) to ~600 (2006). As articulated in Nova Scotia’s Strategy on HIV/AIDS, there is demand within the province to expand...
anonymous testing services, given the difficulty some clients face in traveling to Halifax or Sydney, where current anonymous test sites are situated.\textsuperscript{16,17}

By contrast, in Alberta the use of anonymous testing has diminished, though testing numbers were not provided.\textsuperscript{18,19} Anonymous testing in the province was traditionally available by client request at three STI clinics in Edmonton, Calgary, and Fort McMurray.\textsuperscript{18} An evaluation of anonymous testing at the Calgary clinic found that the option was infrequently requested (only 23 requests between 1998 and 2002), and so this option was repealed in favour of a non-nominal testing approach, which is now used with all clients at the clinic.\textsuperscript{19,20}

In Quebec, the volume of anonymous tests conducted provincially has decreased, from \(~8000\) per year in 1996-98\textsuperscript{21} to \(~1000\) in 2008-09; this decrease corresponds to a restriction of the anonymous test option to the network of 130 SIDEP sites (Services intégrés de dépistage et de prévention des ITSS; SIDEPs are sections of CLSCs, or public health/community health centres, which specialize in providing STI and BBI testing services) and to increased emphasis of the non-nominal option which has been integrated with other STI and BBI test orders\textsuperscript{22,23}. In 2008-09, anonymous testing constituted 7%, non-nominal 14%, and nominal 79% of all HIV tests at CLSCs (Centres locaux de services communautaires).\textsuperscript{23}

US: A 1999 report on federally funded HIV test sites suggested that anonymous testing at that time was declining, from \(~636K\) (25% of all tests at these sites) in 1995 to \(~467K\) (20%) in 1997 (among MSM, 55% tested anonymously in 1997).\textsuperscript{24} More recent data on trends in use of anonymous HIV testing in the US could not be found;\textsuperscript{25} however, one report on HIV testing behaviours of \(~130K\) MSM at 29 US CDC-funded sites in 2007 showed that 27% tested anonymously, suggesting a decline in the use of the anonymous option among MSM testing at federally funded sites.\textsuperscript{26}

2. Outcomes in relation to the testing-to-treatment pathway

Anonymous HIV testing has been posited to have impacts (both positive and negative) on a series of outcomes on a pathway starting with the decision to test and ending with referral to care and partner notification.\textsuperscript{27}

The evidence—or lack of evidence—found for each of these outcomes is outlined below. Systematic evaluations of anonymous HIV testing programs are limited, though studies of the state-wide initiation (Arizona, 1989\textsuperscript{26}) and discontinuation (North Carolina, 1991-93\textsuperscript{29,30}, and again in 1997\textsuperscript{31}) of anonymous HIV testing have yielded unique population-level data on the effects of these “natural experiments”. In Canada, both Ontario\textsuperscript{15,32} and Quebec\textsuperscript{21} have commissioned reports on the experiences with anonymous test options in their respective provinces.

\begin{itemize}
  \item **a. Decision to test**

    Evidence of the effect of anonymous testing on test uptake in general populations is inconclusive; its effect likely depends on the place and time of study and may vary by population. In North Carolina anonymous testing was discontinued in 82 of its 100 counties in 1991, reinstated in response to a Supreme Court ruling in 1993, and then discontinued again from all counties in 1997.\textsuperscript{30,31} An evaluation of the ecological effect of the
initial 1991 interruption in anonymous testing services revealed that overall test volumes continued to increase over the subsequent two years in those counties which eliminated anonymous testing, though this increase was not as great as the increase in counties which retained anonymous testing, and test volumes decreased among MSM in counties which eliminated anonymous testing. An evaluation of the effects of the subsequent state-wide discontinuation of anonymous testing in 1997 showed a 10% decline in the overall volume of testing in the one year after the shift in practice but a recovery in test volumes in the period 13-24 months after the policy change. The introduction of anonymous testing in Arizona in 1989 was also evaluated and found to result in an immediate 24% increase in HIV test demand in the 5 months post-policy change as well as a more sustained 16% increase in the 20 month follow-up period; this increase in testing was most dramatic among MSM, with an increase of 48% in the 20 months following the introduction of anonymous testing. A number of other studies have found that MSM—as well as youth—are more likely to use anonymous testing, where available.

Client preferences in relation to anonymous versus nominal testing have also been measured, and such results can serve as a proxy to understand expected impact on the offer of anonymous testing on test uptake. These studies have produced mixed results. In a 1990 study from Toronto’s Hassle Free Clinic 30% of clients said they would not have been tested if anonymous testing had not been available. In a more recent 2010 evaluation of 17 anonymous test sites in Ontario, 39% said that the availability of anonymous testing was the primary reason for choosing that particular testing location, and clients in “high-risk” groups (MSM, from HIV-endemic countries, IDU, and women reporting “high risk” behaviours) were more likely to ask for anonymous testing (86% versus 60%). Other surveys from the US and elsewhere support these Ontario findings, suggesting that name-based reporting of HIV is a deterrent to testing, especially among stigmatized and high prevalence sub-populations, such as MSM, immigrants, and youth. By contrast, other studies have concluded that concerns related to named reporting are relatively infrequent and insignificant when considering the multitude of factors that contribute to avoidance of testing. In a 2005 multi-site ethnographic study, Grusky et al have commented on these mixed results about client preferences and noted that while these client preference surveys are each useful in their particular place and time, extrapolating the findings is difficult, and mixed results likely reflect differences in persons/groups seeking testing, as well as in how anonymous versus nominal testing is described to prospective testers.

b. Test positivity: An evaluation of HIV testing in Belgium from 1990 to 2002 revealed a rate of positivity seven times higher at anonymous test sites—which administered ~25K of the 7M HIV tests conducted in that country between 1990 and 2002—versus nominal test sites (1.11% versus 0.15%). Likewise, ecological data from Ontario, 1992-2002, show that while only 3.9% of the ~3M HIV tests conducted in the province were anonymous, 5.4% of those testing positive had tested anonymously (test positivity: 1.10% among anonymous testers versus 0.48% among nominal testers). More recent data from a 2007 analysis of MSM testing at US CDC-funded sites showed higher positivity among those testing nominally (4.3% versus 2.6%); however, multivariable analysis with adjustment for other factors removed this association, suggesting that it was confounded, perhaps by test site type (i.e., clinical versus non-clinical).

c. Receipt of results: Where evaluated (and reported), rate of return for test results at anonymous sites appears high, though many of these reports have been anecdotal, and rates are rarely compared with those in nominal test settings. A recent 2010 evaluation including
pre-test client and provider surveys at Ontario anonymous test sites suggested no difference in “certainty” that the client would return for results (91% among anonymous testers versus 87% in non-anonymous testers). Other reports from the Ontario experience have stated: “the rate of return is very high at the anonymous test sites” and “anonymous testing sites that have been in operation for many years report that clients usually do return at some point—often several months later...” without giving estimates of return rates, though one document from the Canadian HIV/AIDS Legal Network notes that in 2000, 92% of clients of the Hassle Free Clinic returned for their results. A 1986-7 study from Oregon found no difference in return rates between anonymous and nominal test sites, with an overall return rate of 94%. Likewise, a 1991-4 study of a St. Louis public health clinic found no difference in return rates among 251 HIV-positive men: 82% among anonymous testers versus 79% among nominal testers. In the 1991-2 North Carolina evaluation, those testing nominally were actually less likely to receive their results (70% versus 92%); however, this was a population-wide study, and those testing nominally were likely testing as part of routine STI screening and may not have specifically sought HIV testing. A 1997-98 study of anonymous testers in Cleveland found that only 42% returned for results; however, this study was limited to ~300 working, uninsured, urban adolescents, and no comparison with return rates in nominal test settings was provided. A 2002 study with a broader study population found a higher return rate of 86% at 61 anonymous test sites in New York State.

d. Access to care: A multi-US state evaluation of anonymous HIV testing published in 1998 found that anonymous testing is associated with testing closer to the time of infection—as measured by CD4 count and time to AIDS diagnosis. Other subsequent studies have found that anonymous testing is associated with delayed entry into care in relation to receipt of HIV positive test result; however, this finding is distinct from that of the above report in that the first study looked at time from infection to care, while the latter two studies looked at time from test result to care. Furthermore, the effect of anonymous testing on delayed entry to care (i.e., >3 months) was small in both of the latter studies and statistically insignificant in one (AORs 1.24 [1.03-1.51] and 1.25 [0.97-1.61]). The beneficial impact of testing sooner after infection may offset the detrimental impact of delayed entry to care from time of diagnosis; this is supported by the above studies with data which show higher first CD4 counts among anonymous testers. The 1991-4 evaluation of seropositive men at a St. Louis public health clinic also supports this interpretation. Although more nominal (79%) than anonymous (53%) testers accepted referrals to care, 24% of nominal testers—versus 8% of anonymous testers—had tested before, suggesting that clients use anonymous testing as a first step in the process of accessing care.

e. Partner notification: After anonymous testing was eliminated from 82 counties in North Carolina in 1991, the mean number of partners notified per index case was higher in those testing nominally, both in counties which eliminated the anonymous option and in those which retained it (0.62 and 0.61, respectively, versus 0.23 for those testing anonymously in the 18 counties which retained the option). In the St. Louis evaluation, those testing nominally were also more likely to agree to partner notification (50% versus 36%), though this difference was not statistically significant.

3. Other population outcomes (cost effectiveness)

One cost-effectiveness analysis from Ontario, 2004, supports the use of a mixed model of both anonymous and nominal testing over one in which only nominal testing is offered, with a
favourable cost-effectiveness ratio ($63,000 per quality adjusted life year gained); however, the details of this analysis are not available [authors have been contacted].

SUMMARY OF EVIDENCE

Trends in use of anonymous testing at population level:
- Recent trends in the use of anonymous HIV testing vary by jurisdiction.
  - In two Canadian provinces where the availability of anonymous testing has been maintained or expanded, uptake has been sustained in a subset of testers.
  - Elsewhere (in two other Canadian provinces surveyed, as well as in the US), use of anonymous testing appears to have decreased over time.

Outcomes on testing-to-treatment pathway:
- It is difficult to make any broad conclusions regarding demand for anonymous testing, as this seems to be highly dependent on client characteristics.
  - Some studies have suggested that MSM and youth are more likely to use anonymous testing where it is available.
  - We may consider that at least some HIV-infected and unaware persons would not seek testing if not given an anonymous testing option, though the scope and motivating factors are difficult to definitively describe.
- At least two population studies have shown higher HIV positivity among those testing anonymously. One other study (from the US) found higher positivity among those testing nominally; however, this difference was removed after adjusting for confounders.
- There is not strong evidence to suggest any significant difference in rates of return for test results between anonymous and nominal testers (based on 4 studies with comparison arms).
- There is some evidence, including from broad, multi-site studies in the US, to suggest that anonymous testers test earlier in the course of infection, though they may take more time before accessing care, after the time of diagnosis (based on 4 studies).
- Two studies suggest that anonymous testers are less likely to complete partner notification at the time of testing; however, these studies did not follow anonymous testers for a long period of time.

Other population level outcomes
- There is insufficient evidence regarding the cost-effectiveness of anonymous testing.

IV. BEST PRACTICES IN CANADA

Through the environmental scan, provincial counterparts shared several best practice and guideline documents, which address many of the operational questions related to anonymous testing.

Staff configuration, workload, training
In Ontario and Nova Scotia, the legislative exemption which allows for anonymous testing requires that testing be accompanied by adequate pre- and post-test counseling (see: [www.e-laws.gov.on.ca/html/regs/english/elaws_regs_900569_e.htm](http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_900569_e.htm) [S5, P1], and [http://www.gov.ns.ca/Just/regulations/regs/hpahiv.htm](http://www.gov.ns.ca/Just/regulations/regs/hpahiv.htm)). As such, pre/post-test counseling training is a fundamental component of the program in those provinces.

Anonymous testing and counseling in Ontario may be offered by a range of service providers, including social workers, nurses, nurse practitioners, midwives, and physicians. At Hassle Free Clinic in Toronto, they administer approximately 5000 HIV tests per year (among >25000 client visits). A typical shift at Hassle Free is staffed by 2-3 physicians, 5-6 staff (who do most of the HIV testing and counseling), and 2-3 volunteers. Of the 5-6 staff, at most 1 is a nurse, and the remaining staff are unregulated health professionals (counselors, some with social work training), who are performing HIV test counseling duties as part of the delegated responsibilities of a physician.

**Reporting and surveillance**

Reporting and evaluation have been a key part of the anonymous test programs in Ontario, Nova Scotia, and Quebec. In these provinces anonymous tests are accompanied by the completion of intake and feedback forms which collect information about demographics (age, gender, ethnicity), motivation for testing, sexual behaviours, drug-using behaviours, other possible exposure factors for HIV, health histories, and opinions about the quality of service. This information is reported and collated for test-negatives as well as test-positives (in NS, this reporting requirement is articulated in the legislation).

In Ontario, if a client has been tested before, he/she may bring a previous unique “patient identification number” so the counselor can link the new test to previous tests. According to Hassle Free Clinic, it is not uncommon for frequent testers (especially those with ongoing risk, e.g., gay men/MSM, clients with HIV-positive partners) to consistently bring their ID number to testing visits; thus, a longitudinal testing history for these clients can be constructed and used for surveillance/evaluation.

Positive test results from clients tested anonymously are still reported to public health; however, the details accompanying such reports vary from province to province. In Nova Scotia this report must include the anonymous code and risk factor information.

- In Nova Scotia the anonymous test code is composed as follows: YOB (4 numbers) + gender (1 letter) + county of residence (first 3 letters) + testing site (2 numbers) + client number (4 numbers, sequentially assigned by testing counselor).
- In Ontario the code is composed of the anonymous test site number and the patient identification number. Requisition forms and adhesive labels (for client, clinic log book, and specimens) are pre-numbered, and these numbers are assigned to clients sequentially.

De-duplication of reported HIV detections— among both those who test multiple times anonymously and those who test anonymously and then re-test nominally—may be an additional process requirement for surveillance.

US CDC recommendations for HIV surveillance practice state that “HIV-infected persons who are initially tested anonymously are eligible to be reported to CDC’s HIV/AIDS surveillance database only after they have had HIV infection diagnosed in a
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[nominal] testing setting.” The CDC and Council of State and Territorial Epidemiologists similarly recommend that states collect surveillance reporting of new HIV diagnoses exclusive of anonymous tests.  

Achieving and maintaining anonymity at clinic level

- Appointments for anonymous testing are recommended so that the provider can ensure the client has adequate time for pre-test counseling. Only first name should be recorded when making an appointment, and this need not be a real name.
- Neither Ontario nor Nova Scotia require that a consent form be signed for testing.
- When anonymous testing is offered at a clinic which provides other STI and clinical care under the client’s real name, the medical chart should note that “HIV was discussed with client” but with no indication of testing, results, or cross-reference to the unique anonymous client ID. At Hassle Free Clinic, nominal HIV testing is not available. If a client requests nominal testing, he/she is directed to another clinic.
- Anyone presenting for HIV testing should be offered or referred to other STI/sexual health prevention services, including STI testing, hepatitis testing, and vaccines. Separate charts may be kept for this purpose, with no cross-referencing of charts/records. The provider should explain to the client the differences in nominal or non-nominal STI testing versus anonymous HIV testing and accompanying reporting processes.
- Clinic documentation should include the following for each anonymous test ordered:
  - Client identification number
  - Code word chosen by client (e.g., mother’s maiden name)
  - Client’s year of birth and gender
  - Date of the test
  - Risk(s), from intake form
  - Test results
  - Date client received results

Pre-test counseling (i.e., pre-test discussions)

- As noted above, pre-test counseling is considered a fundamental component of anonymous testing. If clients refuse pre-test counseling, it is considered appropriate to refuse testing in Ontario and Nova Scotia, given that pre-test counseling is a legislative requirement of anonymous testing.
- In addition to information provided before administering a nominal HIV test, anonymous pre-test counseling should include an explanation of the anonymous testing system and reassurance that no identifying information is recorded in the chart.

Provision of results and follow-up

- It is recommended that clients make an appointment to receive anonymous test results.
- Before giving results, providers should cross-check the unique ID provided to the client at the time of specimen collection as well as the year of birth.
- Clients who are HIV-positive can choose to give their unique ID to the treating physician, which then allows linkage of test results.
Clients may be asked to give a code word at the time of testing (e.g., mother’s maiden name). This can be used along with year of birth and date of testing to find test results, if the client loses the unique ID number.

In Ontario and Nova Scotia, clients are encouraged to receive all results in person. In the unusual circumstance where a client is unable to return in-clinic, results may be given by phone. In this case, clients should confirm a pre-specified code word in addition to the unique ID and year of birth. In Nova Scotia clients receiving results by phone are encouraged to arrange a 45-minute appointment to ensure adequate post-test counseling.

If possible the counselor who does the pre-test counseling should also draw that same client’s blood and provide post-test counseling to that client, in order to maintain confidentiality/anonymity to the extent possible.

In Ontario anonymous test sites tend to see a number of clients who are uninsured, and so anonymous test sites should be prepared to identify organizations which can assist in providing care and treatment to people who are uninsured.

**Selection of anonymous test sites**

- In Ontario anonymous HIV test sites are designated under the *Health Protection and Promotion Act*, and this designation is not transferable.
- In 2007 when Ontario expanded their anonymous test sites, the AIDS Bureau put out a call for proposals, and they encouraged sites from diverse regions/settings to apply. As a result, anonymous testing is now available in 23 of the 26 health units in the province.
- Quality assurance is a key component of selecting and maintaining anonymous test sites in Ontario. The AIDS Bureau ensures that each site has adequate staffing and training to offer anonymous testing.
- In Nova Scotia the following criteria are proposed for selecting additional anonymous test sites in the province:
  - Anonymity (as perceived by individuals using the location; per mechanisms in place to ensure anonymity at the organization; use of a multi-service environment, where access does not imply HIV testing)
  - Philosophy (re: integral nature of counseling; willingness to follow protocols related to HIV testing, follow-up, evaluation, etc.)
  - Responsiveness to client needs (involvement of local community; flexible hours; flexibility in meeting special needs of clients)
  - Accessibility (to region, to target groups)
  - Capacity (skilled staff; able to handle volume of tests; able to maintain expertise; able to provide efficient service and quality service)
SUMMARY OF BEST PRACTICES

There are several noteworthy challenges in the implementation of anonymous testing, including additional staff training, additional surveillance and evaluation systems, special procedures for identifying clients and maintaining anonymity at the clinic level, special practices for ensuring receipt of test results, and careful consideration of the placement/selection of anonymous test sites in a manner which is equitable for the entire population. Nonetheless, as demonstrated by the experience in multiple Canadian provinces and US states, these challenges are not insurmountable.

V. HIGHLIGHTS FROM LITERATURE

A full reference list for the above literature review is provided below; however, the quality of published studies and extent to which they directly investigate questions about the impact of anonymous testing varies substantially. Thus, a selected bibliography is provided here. These seminal papers are recommended for those wanting a more detailed review of published evidence in relation to the anonymous HIV test option:


For a summary of recommended practices in the offer of anonymous testing in Ontario, consult:

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Jessica Halverson, PHAC
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