Anonymous Testing Pilot Evaluation

BACKGROUND

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.[1,2] While this non-nominal reporting option is available province-wide, much confusion exists among clients and practitioners alike regarding its uses and limits. Non-nominal reporting in BC has declined over time from a high of 37% in 2004 to 11% of newly diagnosed HIV cases in 2014 choosing non-nominal reporting.

Pervasive stigma associated with HIV continues to pose a barrier to accessing testing across multiple populations in BC; available data confirms that specific concerns regarding confidentiality or reporting is an issue for a small proportion of persons not testing for HIV. In 2003, Wardman et al conducted interviews with 219 Aboriginal people living in BC, of which approximately one-third reported confidentiality concerns related to their HIV test results.[3]

In addition, in 2008-09, 4% of MSM in Vancouver who had not recently tested identified "being afraid of having their name reported" as a reason for not testing.[4] More recently, a national online survey highlighted concerns about confidentiality of HIV testing remaining a barrier for a small but significant number of gay and bisexual men in BC, finding that 15% of HIV negative or untested men who did not test or delayed testing in past 12 months cited a lack of anonymous HIV testing as a barrier. [5] These men were more likely to identify as bisexual or straight, be partnered with women, live in the suburbs, not be out to health care providers, or out in general, report behaviour that risks HIV transmission, or perceive self at risk for HIV. [5]

Finally, in qualitative research many youth in BC – particularly those in northern or rural areas - discuss concerns about privacy and confidentiality of STI testing sites as potential barriers to accessing testing services, and travelling in order to access confidential testing services.[6,7] Similarly, clinicians report individuals travelling from other parts of BC to Vancouver to test; at clinics operated by BCCDC, between 1-2% of all clinic clients each year are not residents of the Lower Mainland.

Anonymous HIV testing (AHT) allows a person to test without the collection of identifiable or contact information and to retrieve their results using a numbered code known only to the client without the collection of identifiable or contact information. The person tested must provide their code to retrieve the result. Anonymous testing is an addition to, not replacement of, existing HIV testing options (nominal testing, non-nominal testing/reporting). In the event of a client testing positive anonymously, nominal testing was required to access treatment.

Anonymous testing is an additional option that may help to address confidentiality issues in BC. An environmental scan and literature review of anonymous HIV testing programs in Canada and elsewhere demonstrated that anonymous testing reached some individuals who would not have tested or delayed testing if an anonymous option was not available. In addition, those who test anonymously may have a

higher positivity rate and test earlier in their HIV infection. For more information, please refer to the *Anonymous HIV Testing: Evidence Review and Environmental Scan* as prepared by BCCDC.

In March 2013, BCCDC launched an anonymous HIV testing pilot after extensive consultation with public health nurses and physicians throughout BC and with the permission of the Provincial CD Policy Committee. A document titled, *Anonymous HIV Testing Pilot: Procedures for Participating Sites* was developed, published on the BCCDC website and shared with pilot sites. In addition, training plans were created with each of the pilot sites and co-facilitated by BCCDC and pilot site leads.

The following document outlines the process of implementing the pilot as well as the evaluation of the findings.

DEFINITIONS:
The terms anonymous testing, non-nominal testing, pseudonym testing and non-nominal reporting after are often used interchangeably and the nuances of each are often misunderstood by both practitioners and clients. For the purposes of the pilot, each of the following HIV testing and reporting options were defined as follows:

- **Nominal HIV Testing**: HIV testing in which the test is conducted and reported using the client's full name, address and contact information (i.e. email address or phone number).

- **Non-Nominal Testing**: HIV testing in which the test is conducted using the client's initials per agency standards.
  Note: In BC, the ability to test under initials is not covered by regulation; rather this is a matter of practice/policy of the provider or site ordering the test.

- **Pseudonym HIV Testing:** HIV testing in which the test is conducted using a pseudonym for the client.
  Note: In BC, the ability to test under a pseudonym is not covered by regulation; rather this is a matter of practice/policy of the provider or site ordering the test.

- **Non-Nominal Reporting**: A client who has a nominal, non-nominal or pseudonym HIV test (e.g., ordered using full name, pseudonym or initials) and receives a positive result does not have their name, address or contact information reported to public health.
  Note: The Communicable Disease regulation applies specifically to non-nominal reporting to public health and not to the non-nominal ordering of tests. Non-nominal HIV reporting is identified through checking a tick box on the laboratory requisition form, or is assumed if known to be a non-nominal test.

- **Anonymous Testing**: HIV testing and reporting in which results can be linked to the person being tested using a code known only to the client. No identifiable or contact information is collected and the person being tested must provide their anonymous testing code in order to receive their result.

PILOT OBJECTIVE:

The objectives of the anonymous HIV testing pilot were as follows:

- Increase uptake of HIV testing in clients who may not test or delay testing due to confidentiality concerns (i.e. MSM, youth, healthcare workers)
- Optimize connection to follow-up, care and support for those who test HIV positive

PILOT PLANNING:

During the planning phase of the pilot, over 30 consultation sessions were held with each of the Health Authorities, the First Nations Health Authority, community organizations such as Positive Living BC and the Pacific AIDS Network. In addition, Hassle Free Clinic in Toronto was consulted extensively for advice and suggestions regarding operational and logistical planning.

Legal opinion from the Ministry of Health was sought with support given for proceeding with the anonymous HIV testing pilot. It was determined at that time that there was no need to change the CD regulation to permit anonymous HIV testing. An ethical review[8] was also conducted and found that not offering anonymous HIV testing BC could be considered unethical as it forced those with extreme confidentiality concerns into lying to a practitioner about their name/contact information.

A comprehensive evaluation plan for the pilot was developed, then circulated and approved by the CD Policy Committee in September, 2012 and is further detailed below. A complete timeline of the pilot is available in Appendix 1.

Anonymous HIV Testing test kits (see Appendix 2) were provided by the BCCDC and training was provided jointly between the BCCDC and the pilot site leads.

PILOT OUTLINE:

The *Anonymous HIV Testing Pilot: Procedures for Participating Sites* instructed health care providers to continue to offer nominal, non-nominal and pseudonym HIV testing options during the pilot according to their current practice, and it was not expected that all clients who presented for HIV testing at a pilot site were offered anonymous HIV testing. Rather, it was recommended that options for additional confidentiality (such as non-nominal, pseudonym and anonymous HIV testing) be offered when a provider identified that the client had specific concerns about confidentiality during the pre-test assessment.

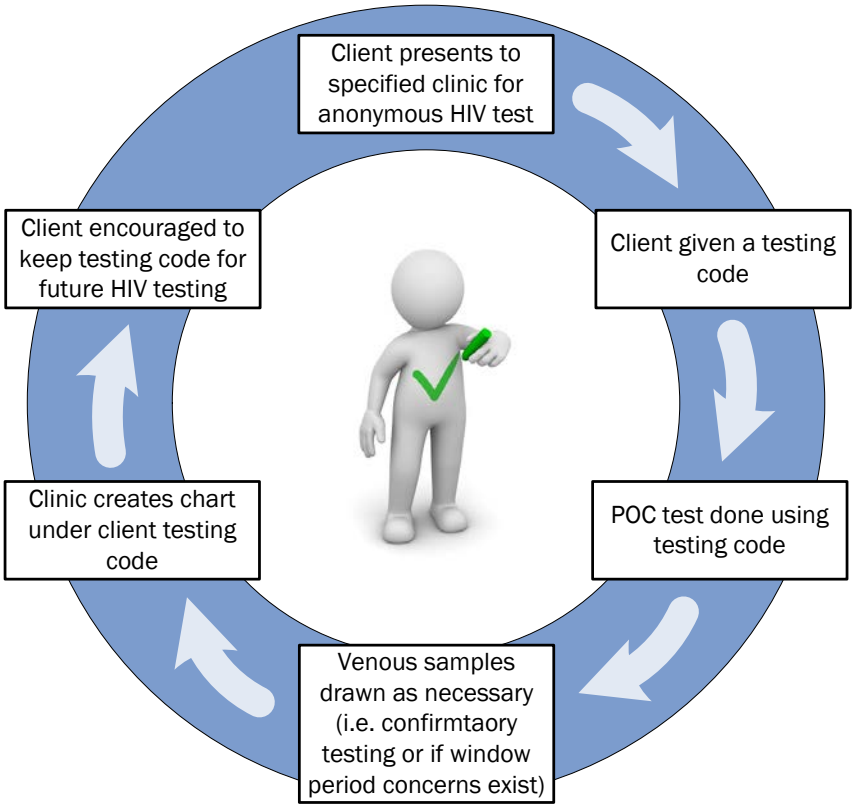
If the client chose to be tested anonymously for HIV, the preferred option was to offer a POC HIV test followed by a venous sample if any of the following conditions applied: a) if the client qualified for NAAT testing b) there was a concern about the window period or c) if the POC test was positive.

For each anonymous HIV test, a separate chart was created with no connection between anonymous HIV testing and the client's identity, and under no circumstances was the testing provider to connect a nominal or pseudonym chart to an anonymous chart.

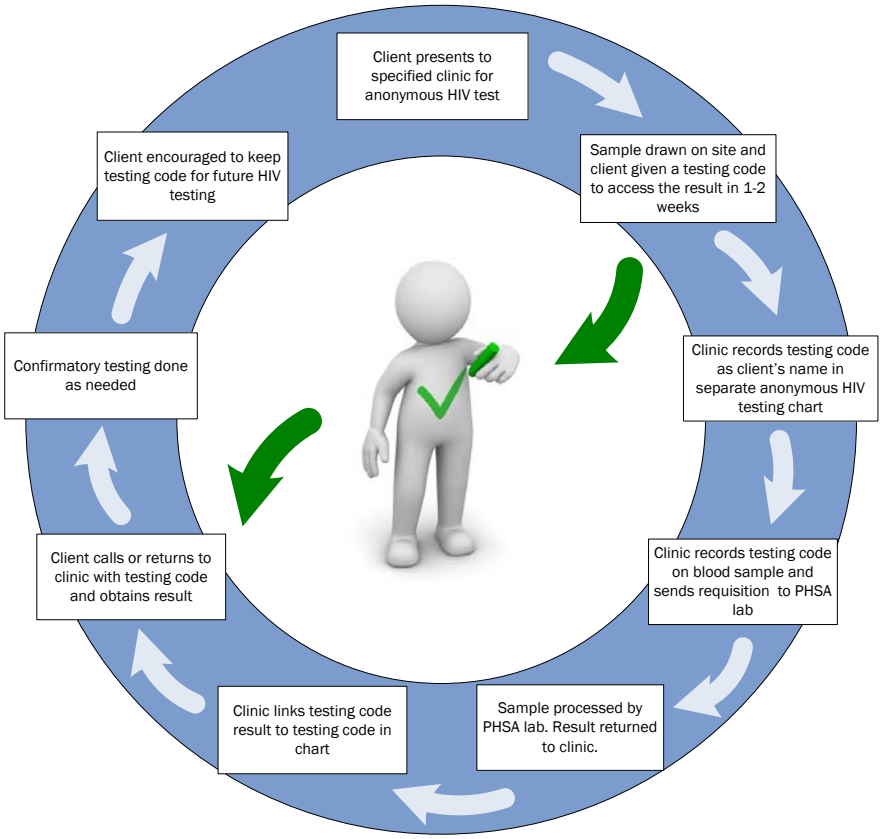
Pilot sites were provided with anonymous HIV testing kits (see Appendix 2) inclusive of an anonymous HIV testing number, a tailored requisition, an information card and survey (see Appendix 3) for each tester with instructions to use one kit per anonymous client.

Providers were instructed that anonymous testing applied to HIV only and not for STI testing and that anonymous HIV testing numbers were not to be used in place of a client's name when sending samples for STI testing.

For POC HIV tests done anonymously, the diagram below provides an overview of the process.



For serology HIV tests done anonymously, the diagram below provides an overview of the process.



PILOT SITES:

The pilot officially launched at the BCCDC Provincial STI Clinic at 655 West 12th Avenue in Vancouver in March, 2013. The timelines for the start of anonymous testing at the other sites are as follows:

- May 2013: Fraser Health Authority, Blood Borne Pathogens team
- December 2013: Bute Street Clinic and HIM on Davie
- January 2014: STOP Team began offering at HIM on The Drive and outreach locations
- March 2014: St. Paul's Hospital Immunodeficiency Clinic (IDC)
- May 2014: Cook Street Clinic in Victoria.
- January 2015: Interior Health Authority, Interior Health Outreach Team

PILOT PROMOTION:

Online
Regional Health Authorities and community organizations were consulted regarding the best methods for targeted communications for anonymous HIV testing and were key in sharing information about the pilot in their communities. Sample blog posts, tweets and Facebook posts were shared with community organizations regarding the pilot and they were encouraged to use these at their discretion.
Information about the anonymous HIV testing pilot was also made available in several online venues as follows:

- *SmartSexResource.com*: an informational page outlining the differences between anonymous, non-nominal testing and non-nominal HIV reporting was created. In addition, there was also a page created which provided more detailed information regarding anonymous HIV testing. A feature was also added to the *SmartSexResource.com* clinic finder which allowed people to search the website for clinical sites where anonymous HIV testing was available. Blog posts for health care providers were written and published on SmartSexResource.com regarding the launch and ethics of anonymous HIV testing.
- *Squirt.org*: Banner ads and e-blasts to members were purchased and sent out over a month-long campaign.
- *Posts on Sex-seeking websites*: A BCCDC nurse involved in online chat room messaging on PERB.cc and Squirt.org posted announcements to notify patrons that anonymous HIV testing was available and provided a link to the smartsexresource.com website.
- *Regional Health Authority pages*: RHAs were encouraged to promote the pilot as they saw fit to their target populations including internal health promotion and workplace health websites and externally facing websites directed towards clients.
- *BCCDC Twitter*: tweets about the pilot were posted every 2 weeks over the course of several months.

Print

- *Posters and wallet cards:* were made available for pilot sites to display in their clinics. The information on the printed material advised that there were many ways to get an HIV test at that location without specifically advertising anonymous HIV testing.

EVALUATION PLAN:
The evaluation plan circulated to the CD Policy committee in September 2012 focused on basic characteristics of anonymous HIV testers, test volume and positivity, clients receipt of results, referrals to care, partner notification outcomes, client reasons for anonymous HIV testing as well as previous history of HIV testing. The information below details the findings from the pilot evaluation.

Part 1: Analysis of Test Volumes and Positivity

Test Volumes and Positivity (Febuary 2013 through March 2015)
TVP_1. What was the test volume for the pilot program?
TVP_2. What was the positivity for the pilot program?
TVP_3. What proportion of anonymous clients returned for their results?
TVP_4. What populations accessed anonymous testing (age, gender)?

Results
Test Volumes and Positivity (February 2013 through March 2015)

TVP_1. What was the test volume for the pilot program?

In the first two years of the pilot, 283 clients tested anonymously for HIV. 189 choose to have only a POC test, 38 choose to have only a serological HIV test and 56 choose to have both a POC and serology test.

In 2013, one site in BC offered anonymous HIV testing from March to December and as such only 12 clients were tested anonymously. However, 206 clients were tested in 2014. This amount of testing appears to be stable for 2015 with 65 clients tested in the first quarter.

Most of the clients were tested in Vancouver (n=247, 87.3%). Over 50% of tests were conducted through VCH STOP Team (n=143) followed by Bute clinic (n=37), 655 West 12th clinic (n=30), Victoria STI clinic (n=29), HiM on Davie (n=26) and IDC (n=11) (see Table 1 for further breakdowns).

TABLE 1

Clinic	Number of Clients January 2013 to March 2015 (N=283)	Percent
VCH STOP TEAM (Vancouver)	143	50.5%
Bute Clinic (Vancouver)	37	13.1%
655 West 12th (Vancouver)	30	10.6%
Victoria STI Clinic	29	10.2%
HiM on Davie (Vancouver)	26	9.2%
IDC (Vancouver)	11	3.9%
New Westminster HiM	4	1.4%
Kelowna Health Outreach	2	0.7%
Nelson Health Outreach	1	0.4%

TVP_2. What was the positivity for the pilot program?

Of the 283 clients who tested, 278 tested negative. Of the 5 clients who had reactive tests, 2 were reactive POCs without a standard serology test and 3 had positive serology tests. The testing sites reporting positive tests include VCH STOP (n=3), 655 West 12th Street clinic (n=1), and Bute Street clinic (n=1). The positivity for the pilot was 1.8% (5/283).

TVP_3. What proportion of anonymous clients returned for their results?

Nearly all (99.5%) of the people opting for a POC test (n=188 clients) received their results. For those who choose a serology test alone (n=38 clients), 22 (58%) returned for their results. Those who choose both a POC and serology test (n=56 clients) all (100%) received their POC results and over half, 52% (29 clients), returned for their results.

TVP_4. What populations accessed anonymous testing (age, gender)?

Only year of birth and gender are collected from clients who test anonymously. A little under half of the clients are under 40 (<30 years old, n=52, 18.4% and 30-39 years old, n=86, 30.4%); most were male (n=249, 88%) (see Table 2 for further breakdowns).

TABLE 2

Demographics		Number of Clients(N=269)	Percent
Gender	Female	22	7.8%
	Male	249	88.0%
	Transgender	1	0.4%
	Unknown/Blank	11	3.9%
Age group	<30yrs	52	18.4%
	30-39yrs	86	30.4%
	40-49yrs	67	23.7%
	>=50yrs	69	24.4%
	Unknown	9	3.2%

Part 2: Reasons for Anonymous HIV Testing

SR_1. Are people in BC unlikely or unwilling to get HIV tested because of lack of availability of anonymous testing options?
SR_2. Are people more likely to test if there is an anonymous HIV testing option?
SR_3. What are the socio-demographic groups/sub-populations accessing anonymous HIV testing?
SR_4. What are the reasons that clients test anonymously?
SR_5. How do clients find where to test anonymously?

Method:

Participants

From January 2013 to March 2015, 269 clients tested anonymously in eight clinics or sites in Vancouver Coastal Health, Island Health, Fraser Health and Interior Health Authorities. Of these clients, a subset of 87 clients filled out confidential surveys.

Procedure

Anonymous HIV Testing volumes are collected through the STI Information System (STIIS), a clinical charting system and through the Anonymous HIV Testing database maintained by clerical staff at BCCDC. Serological tests ordered through AHT are located in SunQuest, the laboratory testing database maintained by BC Public Health Microbiology and Reference Laboratory for data quality purposes.

When clients opt to test anonymously at clinics/test sites, the medical staff offers a one-page survey for clients to fill out confidentially. Of the 283 clients, 87 returned a completed survey for a response rate of 31% (87/283).

Analyses

Totals and percentages are reported. Demographics between anonymous testers who fill out the survey will be compared to the overall group of anonymous testers to assess whether the sample of survey participants differ. When possible, chi-square analyses are calculated to test associations.

Survey Results (January 2013 through March 2015)

Comparisons on age and gender for all anonymous HIV testers were compared against the age and gender of those who chose to fill out the one-page survey to determine whether differences could be noted between participants who fill out the survey and those who decline. Because no other demographics are collected from anonymous HIV testers, no other comparisons could be made.

Comparisons of gender and age groups distributions of all anonymous testers (see Table 2) with those who filled out the survey (see Table 3) show relatively similar patterns. There appears to be no differences based on gender or age between participants in the survey and the overall group of anonymous HIV testers.

TABLE 3

Demographics		Number of Clients(n=87)	Percent
Gender	Female	8	9.2%
	Male	79	90.8%
Age group	<30yrs	20	23.0%
	30-39yrs	27	31.0%
	40-49yrs	17	19.5%
	>=50yrs	22	25.3%
	Unknown	1	1.1%

SR_1. Are people in BC unlikely or unwilling to get HIV tested because of lack of availability of anonymous testing options?

To assess this question, two survey questions were analyzed: (1) Did you come to this clinic because you knew that anonymous HIV testing was available? and (2) If anonymous HIV testing were not available, would you have still tested today? Participants could respond "Yes" or "No" to both questions. For the second question, participants also could respond "I don't know" and "Prefer not to say". For the chi-square analysis, only "Yes" and "No" responses were used and the other responses were recoded as missing.

Of the 87 survey respondents, 59 (68%) reported coming specifically to a clinic that offered anonymous HIV testing. Over a third (n=21, 36%) of the 59 clients who reported going to a specific clinic that offered anonymous HIV testing also indicated that they would not test that day if anonymous testing were not available. This association was significant, X^2 *(1, N=64) = 9.47, p<.01*. Thus, suggesting a relationship between people who specifically seek out clinics that offer anonymous HIV testing and a delay in testing if anonymous HIV testing were not available.

SR_2. Are people more likely to test if there is an anonymous HIV testing option?

In a 2013 CAHR presentation that examined reasons for avoiding or delaying HIV testing, the researchers analyzed data from the 2011-12 *SexNow* survey and found that 15% of gay and bisexual men in BC reported the lack of anonymous testing as the reason for delaying or avoiding HIV testing.[5] This finding suggests that some clients would be more likely to test with an anonymous HIV testing option.

When asked, "If anonymous HIV testing were not available, would you have still tested today?" nearly half the respondents to the client survey (n=42, 48%) reported that they would still have tested without anonymous HIV testing. However, an equal amount of respondents reported some hesitation or potential delay in testing (23 (26%) would not have tested that day, 20 (23%) said they did not know and 2 (2%) preferred not to say).

SR_3. What are the socio-demographic groups/sub-populations accessing anonymous HIV testing?

Of the survey respondents, 79 (91%) were male. The majority of male respondents (n=56, 71%) reported sex with men (MSM). Nearly half (n=41, 47%) were Canadian-born. Most of the respondents identified as White (n=51, 59%).

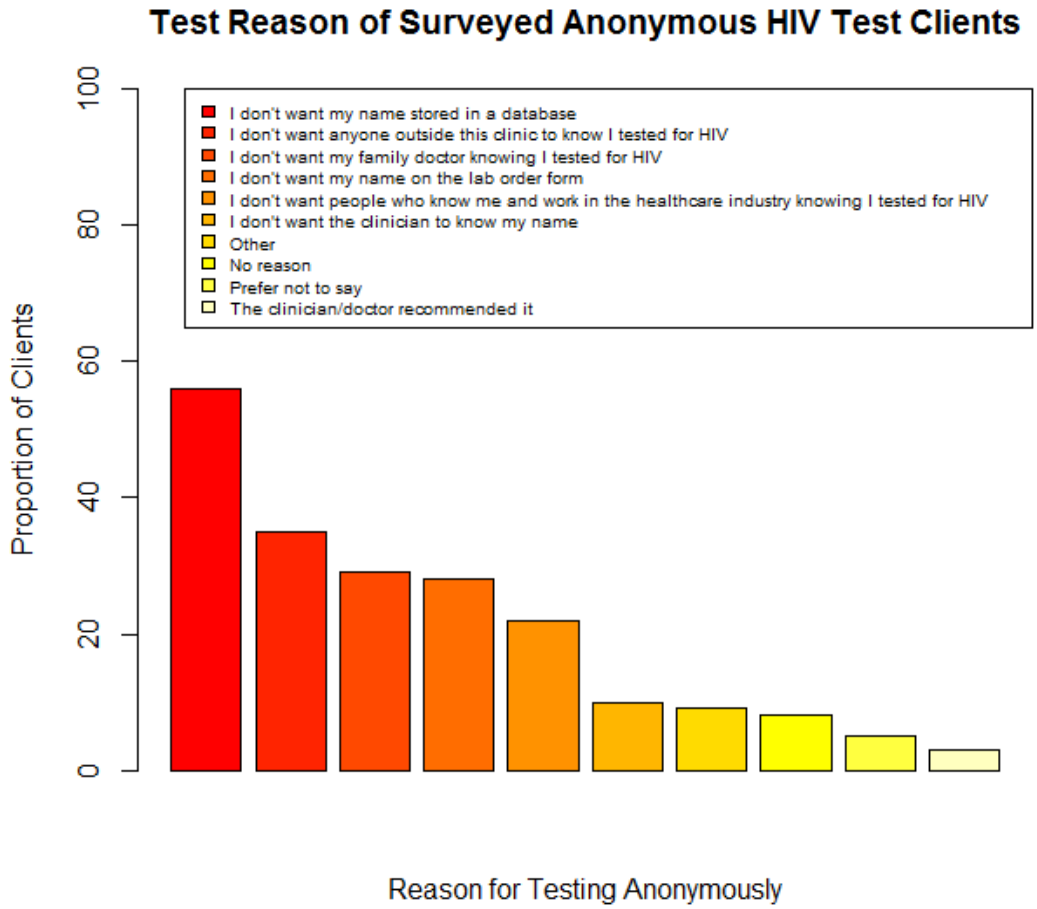
Almost a quarter of respondents (n=21, 24%) responded yes to having ever injected, smoked (excluding pot/marijuana) or snorted drugs using items such as a needle, syringe, cooker, straw or pipe that someone else had used. Therefore, the clients accessing anonymous testing may be at higher risk for HIV.

About a third of the respondents reported having tested in the last 3 months (n=32, 37%) while nearly a quarter of clients reported testing over 2 years ago (n=12, 14%) or never (n=8, 9%). Almost all of those who reported testing previously also reported having negative tests (n=76, 97%) although 2 (3%) reported not getting his/her result.

SR_4. What are the reasons that clients test anonymously?

Participants were asked, "Why did you choose to test anonymously for HIV?" and were provided a list of potential reasons to select from. Multiple choices were allowed (see Figure 1).

FIGURE 1.



The top reasons selected by respondents for choosing to test anonymously was that they did not want their name stored in a database (n=48, 56%); they did not want anyone outside of the clinic they were testing at to know that they tested for HIV (n=30, 35%); and they didn't want their family doctor knowing that they had tested for HIV (n=25, 29%).

SR_5. How do clients find where to test anonymously?

Participants responded "Yes" or "No" to the question, "Did you come to this clinic because you knew that anonymous HIV testing was available?" In a follow-up open-ended question, participants responded to the question, "If yes, how did you hear about anonymous HIV testing at this clinic?". The free-text responses to the follow-up question were grouped into six categories based on their themes: online (e.g. Findclinic.com, HiM website, internet), friends/networks (e.g. friends, my partner, word of mouth), health care providers/clinics (e.g. doctor, nurse told me, another clinic), community setting (e.g. sign at bathhouse, Steamworks, F212), work (e.g. from work, work place) and other (e.g. ? Don't know, assumed it would be available).

More than two-thirds of clients (n=59, 68%) reported coming to a specific clinic because anonymous HIV testing was offered. Of those 59 respondents, 21 (36%) reported hearing about AHT from online sources, 11 (19%) reported learning about AHT through their social networks and 9 (15%) responded hearing about AHT through a health care professional or from a clinic.

Part 3: Analysis of Provider Survey Results

A healthcare provider survey was created and distributed via Fluid Surveys to obtain feedback on provider's experiences offering anonymous HIV testing at their pilot sites (see Appendix 4).

A total of 59 respondents completed the survey. However, as we do not know the number of staff who provide AHT at each site, we are unable to calculate a response rate to this survey. The survey items were grouped into three sections: Roles, Likert items and Other questions. Participants were omitted if 2/3 of the Likert items (i.e. less than 9 Likert items) and other questions section (i.e less than 5 other questions) were not completed. The final dataset consisted of 35 respondents.

80% of the respondents were health care providers who conduct AHT. Some (23%) had administrative or management responsibilities and 26% had responsibilities for training other staff. Clearly, respondents often had multiple roles at the clinic sites as these figures add up to more than 100%. Overall, 89% of respondents strongly agreed or agreed that anonymous testing was an important service to offer and 83% strongly agreed or agreed that there are benefits to AHT even with non-nominal testing and reporting are available.

Respondents to the survey felt confident that they understood the differences between non-nominal testing, non-nominal reporting and AHT, with 91% of respondents agreeing or strongly agreeing to this statement. When asked about the complexity of providing AHT, 66% disagreed that they have avoided offering AHT because they didn't know the clinical process. These responses suggest that the training that healthcare workers received for AHT was effective in preparing staff at the sites for this activity. In terms of the complexity of offering AHT, 37% of providers disagreed that creating a second chart discouraged them from offering AHT to clients and 20% did not agree or disagree with this idea. However, a nearly equal number of providers agreed (25%) that creating a second chart was a deterrent

to offering AHT. 61% of respondents agreed that clients have told them that they come to their testing site specifically because AHT was available.

A total of 24 staff provided additional comments regarding what they saw as the benefits of offering AHT. Common themes reported included encouraging testing/removing testing delays, comfort, confidentiality, patient control of the testing situation and meeting demand. Additionally, 18 staff provided comments on additional problems or negative aspects of providing AHT. Some of the comments included duplicate charting and increased workload, confusion among staff on AHT protocols, clients not receiving their results and increased client confusion between receiving results for STI versus AHT. Also mentioned as a related issue to the difference in receiving results for STI testing and AHT is that there is potential to compromise anonymity when receiving results for both at the same time.

EVALUATION LIMITING FACTORS:

One key factor which limited this evaluation was our inability to compare the anonymous HIV testing rate of return for results to nominal and non-nominal clients at the pilot sites as this data was not readily available from most of the sites.

EVALUATION CONCLUSIONS AND FUTURE CONSIDERATIONS:

Over a two year period a total of 283 clients opted to undergo HIV testing using an anonymous pathway available at seven testing sites in BC. Over half of these tests were conducted by the VCH-STOP nursing team. Of these tests, a total of 5 were positive, yielding a seropositivity rate of 1.8% which is much higher than the background rate of HIV seropositivity at STI clinics in BC.

Of the 87 clients who completed a survey (31% of the total clients who underwent AHT), over two-thirds (68%) reported coming specifically to a clinic that offered anonymous HIV testing. Over a third of these clients also indicated that they would not test that day if anonymous testing were not available. Therefore, it seems that AHT attracts individuals who are more likely to have undiagnosed HIV infection and who may be deterred from testing, if this option was not available.

Among healthcare providers who completed surveys, AHT was viewed as a valuable option to be able to offer clients. There was a mix of opinions on whether the complexity of the process for AHT was a deterrent to offering it. However, 89% of respondents strongly agreed or agreed that anonymous testing was an important service to offer and 83% strongly agreed or agreed that there are benefits to AHT even with non-nominal testing and reporting available.

RECOMMENDATIONS:

The AHT pilot program has now been in operation for close to three years and appears to be valued both by service providers and clients alike. The results of this pilot suggest that AHT provides a subpopulation of clients with particular concerns around privacy with an HIV testing option that is more private than non-nominal testing. As such, it is the recommendation of the evaluation team that AHT continue to be offered at selected sites across BC, and expand to include more options for individuals living outside of Greater Vancouver or Victoria. The transition from a pilot to a fully operational program, will allow the management of the program to become more aligned with other supply and reporting chains in the province, which should reduce the operational burden on BCCDC STI Clinic staff and improve the monitoring of this program.

REFERENCES

1. Public Health Act. Health Act Communicable Disease Regulation. *B.C. Reg. 4/83*.
2. Provincial Health Officer's Report on HIV Reportability. Ministry of Health Planning: Office of the Provincial Health Officer. February 2002. Available at: http://www2.gov.bc.ca/gov/DownloadAsset?assetId=8135C9FD025745EF95166549154C7D8D&filename=hivreportability.pdf
3. Wardman D, Quantz D, Clement K. HIV/AIDS: testing and risk behaviors among British Columbia's rural Aboriginal population. *Int J Circumpolar Health.* 2006;65:313-321.
4. Kanters S, Michelow W, Gilbert M. *Survey and Dried Blood Spot Results: Vancouver Site, MTrack Surveillance System*2010.
5. Gilbert M, Salway Hottes T, Trussler T, Marchand R, Brownrigg B, Ogilvie G, Lester R, Kendall P. Avoidance of HIV testing among gay and bisexual men due to lack of anonymous testing in British Columbia. CAHR 2013 Oral Presentation.
6. Goldenberg S, Shoveller J, Koehoorn M, Ostry A. Barriers to STI testing among youth in a Canadian oil and gas community. *Health & place.* 2008;14(4):718-729.
7. Shoveller J, Johnson J, Rosenberg M, et al. Youth's experiences with STI testing in four communities in British Columbia, Canada. *Sexually transmitted infections.* 2009;85(5):397-401.
8. Unger D, Gilbert M, Brownrigg B. Ethical considerations regarding anonymous HIV testing. September 2012. Available at: http://www.bccdc.ca/NR/rdonlyres/A9F53AB5-EED1-4977-A866-35FEBC2D66B7/0/STI_AnonHIV_Ethical_Considerations_20130507.pdf

APPENDIX 1: Timeline of pilot

- July 2011: discussion of confidentiality of HIV testing by the CD Policy Committee led to agreement for BCCDC to explore an anonymous HIV testing pilot.
- Fall 2011: Literature review and environmental scan of anonymous HIV testing completed by BCCDC.
- Winter 2012: Draft outline of anonymous HIV testing model created based on lit review and environmental scan with Ontario model as starting point.
- Winter/Spring 2012: Consultation with public health agencies to refine model and determine how anonymous testing could be applied in BC:
    - STI BBI Task Group of CD Policy
    - FNHA, VCH, FHA, NHA, IH, VIHA
    - PHSA Labs
- September 2012: Pilot approved in principle by the CD Policy Committee.
- Summer/Fall 2012: Identification of potential pilot sites, development of evaluation plan, legal and ethical reviews completed both supportive of pilot.
- Fall 2012: Evaluation plan, legal and ethical review completed; approval from CD Policy Committee to proceed with provincial pilot.
- Winter 2012/13: Procedures and protocols finalized with input from regions, PHSA Labs, CD Policy; updates provided to Designated Nurses.
- March 2013: Provincial STI Clinic became first anonymous HIV testing pilot site.
- May 2013: Fraser Health Authority, Blood Borne Pathogens team began offering anonymous HIV testing.
- December 2013: Bute Street Clinic and HIM on Davie began offering anonymous HIV testing.
- January 2014: STOP Team began offering at HIM on The Drive and outreach locations
- March 2014: St. Paul's Hospital Immunodeficiency Clinic (IDC) began offering anonymous HIV testing.
- May 2014: Cook Street Clinic in Victoria began offering anonymous HIV testing.
- January 2015: Interior Health Authority, Interior Health Outreach Team began offering anonymous HIV testing.

APPENDIX 2: Anonymous HIV Test Kits

APPENDIX 3: Client Survey

Age Range:

☐ Under 19 ☐ 19-24 ☐ 25-29 ☐ 30-34

☐ 35-39 ☐ 40-49 ☐ 50-59 ☐ 60 or older

Where do you live? (Choose one)

☐ Vancouver

☐ Lower Mainland (other than Vancouver)

☐ BC (outside Lower Mainland)

☐ Outside BC

☐ Outside Canada

Gender:

☐ Male ☐ Transgender: MTF

☐ Female ☐ Transgender: FTM

My sexual partners are (check all that apply):

☐ Men ☐ Transgender: MTF

☐ Women ☐ Transgender: FTM

Where were you born?

☐ Born in Canada

☐ Born outside Canada; where? _____

Year of arrival in Canada: _____

When was your last HIV test?

☐ In the last 3 months ☐ 1-2 years ago

☐ 3-6 months ago ☐ More than 2 years ago

☐ 6 months – 1 year ago ☐ Never

Result of last test:

☐ Positive ☐ Prefer not to say

☐ Negative ☐ Did not get test result

Why did you choose to test anonymously for HIV? (check all that apply)

☐ I don't want the clinician to know my name

☐ I don't want my name stored in a database

☐ I don't want my family doctor knowing I tested for HIV

☐ I don't want anyone outside this clinic to know I tested for HIV

☐ I don't want people who know me and work in the healthcare industry knowing I tested for HIV

☐ I don't want my name on the lab order form

☐ The clinician/doctor recommended it

☐ No reason

☐ Prefer not to say

☐ Other (please specify):_____

If anonymous HIV testing were not available, would you have still tested today?

☐ Yes ☐ Don't know

☐ No ☐ Prefer not to say

Have you <u>ever</u> injected, smoked, or snorted drugs (not including pot/marijuana) using items (such as a needle, syringe, cooker, water, straw, pipe) that someone else had used?

☐ Yes ☐ Don't know

☐ No ☐ Prefer not to say

Do you work in the healthcare industry?

☐ Yes ☐ Don't know

☐ No ☐ Prefer not to say

Do you identify yourself as an Aboriginal person, that is, First Nations, Métis, or Inuit?

☐ Can't remember

Is this your first HIV test in British Columbia?

☐ Yes ☐ Don't know

☐ No ☐ Prefer not to say

If no, how have you previously tested for HIV in BC? (Choose all that apply)

☐ Using my real name

☐ Using a false name

☐ Using my initials

☐ Using an anonymous testing number

If you previously tested using an anonymous testing number, did you give us this number to re-use today?

☐ Yes ☐ No

Did you have STI testing done today (e.g., Chlamydia, gonorrhea, or syphilis)?

☐ Yes ☐ Don't know

☐ No ☐ Prefer not to say

Have you ever previously tested for HIV at this clinic?

☐ Yes, at this clinic ☐ Don't know

☐ Yes, at another clinic ☐ Prefer not to say

☐ No

Did you come to this clinic because you knew that anonymous HIV testing was available?

☐ Yes ☐ No

If yes, how did you hear about anonymous HIV testing at this clinic? _____

☐ Yes ☐ No

If you identify yourself as an Aboriginal person, are you?

☐ First Nations

☐ Métis

☐ Inuit

If you do not identify as an Aboriginal person, what is your ethnic or racial background?

☐ White

☐ Chinese

☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan)

☐ Filipino

☐ Korean

☐ Southeast Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese)

☐ Japanese

☐ West Asian (e.g., Afghan, Iranian)

☐ Latin American

☐ Black

☐ Arab

☐ Other; please specify: _____

APPENDIX 4: Provider Survey

The BC Centre for Disease Control (BCCDC) is currently evaluating the anonymous HIV testing pilot program. It is important for us to obtain the perspectives of health care providers about the pilot to help us understand whether we are meeting clients and providers needs and to help us improve our services. Your name and place of work are not collected and your participation is voluntary. There are open-ended questions in this survey. We encourage you not to provide any identifying information, such as names, ages, or identification numbers, in your answers to open ended questions. You can skip any questions that you don't want to answer. The survey will take 5-10 minutes to complete. If you have any concerns comments or questions about the survey please contact Bobbi Brownrigg, Leader Public Health Initiatives and Innovation, Clinical Prevention Services at BCCDC at bobbi.brownrigg@bccdc.ca. Thank you for your time.

What is your role in the anonymous HIV testing pilot at your site? (check all that apply)

☐ Management or administrative

☐ Supervise staff conducting anonymous HIV testing

☐ Conduct anonymous HIV testing

☐ Provide health care services for patients who have received anonymous HIV testing

☐ Teach other health care providers or students about anonymous HIV testing

☐ Other (please specify) _____

Please check one response for each of the following that best describes your personal perspectives about anonymous HIV testing in your work setting.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree	Don't Know	Not Applicable
Anonymous HIV testing is an important service offered in my work setting	○	○	○	○	○	○	○
I understand the difference between non-nominal testing, non-nominal reporting and anonymous HIV testing	○	○	○	○	○	○	○

I see the benefit of anonymous HIV testing even when non-nominal testing and reporting are available	○	○	○	○	○	○	○
I understand who to offer anonymous HIV testing to and who not to	○	○	○	○	○	○	○
I am comfortable discussing anonymous HIV testing with clients	○	○	○	○	○	○	○
Offering anonymous HIV testing in my work setting encourages people who test nominally to test anonymously	○	○	○	○	○	○	○
I have avoided offering anonymous HIV testing to clients because I don't know the clinical process	○	○	○	○	○	○	○
I have avoided offering anonymous HIV testing because I believe clients should have to provide contact information contact information	○	○	○	○	○	○	○
Discussing anonymous testing with clients takes too long	○	○	○	○	○	○	○
Most clients who chose to test for HIV anonymously also had STI testing done	○	○	○	○	○	○	○
My work setting has the resources needed to	○	○	○	○	○	○	○

implement anonymous HIV testing							
Creating a second chart when a client has anonymous HIV testing and STI testing discourages me from offering anonymous HIV testing to my clients	○	○	○	○	○	○	○
I am concerned that my work setting doesn't offer anonymous STI testing	○	○	○	○	○	○	○
Clients have told me they came to this testing site specifically because anonymous HIV testing is available	○	○	○	○	○	○	○

Please list any benefits or positive outcomes that have resulted from the implementation of anonymous HIV testing in your work setting.

Please list any problems or negative outcomes that have resulted from the implementation of anonymous HIV testing in your work setting.

Please list any changes you would suggest be incorporated into the anonymous HIV testing pilot.

Please fill out this section only if you provide HIV or STI testing to a client(s).

How many clients do you see in a typical week?

- ○ 0-25
- ○ 26-50
- ○ 51-75
- ○ 76-100
- ○ 101 or more

How many clients have you discussed anonymous HIV testing with since the pilot began in your work setting?

- ○ None
- ○ 1-5 clients
- ○ 6-10 clients
- ○ 11-20 clients
- ○ Greater than 20 clients
- ○ I don't know

How many clients have you provided anonymous HIV testing to since the pilot began in your work setting?

- ○ Zero
- ○ 1-5 clients
- ○ 6-10 clients
- ○ 11-20 clients
- ○ Greater than 20 clients
- ○ I don't know

Please fill out this section only if you supervise staff who provide anonymous HIV testing.

How often did anonymous HIV testing charts contain identifiable information?

- ○ Never
- ○ 1-5 occurrences
- ○ 6-10 occurrences
- ○ Greater than 10 occurrences
- ○ Unknown

How often did nominal or non-nominal testing charts contain a client's anonymous HIV testing information?

- ○ Never
- ○ 1-5 occurrences
- ○ 6-10 occurrences
- ○ Greater than 10 occurrences
- ○ Unknown

Survey completed! Thank you for participating.