



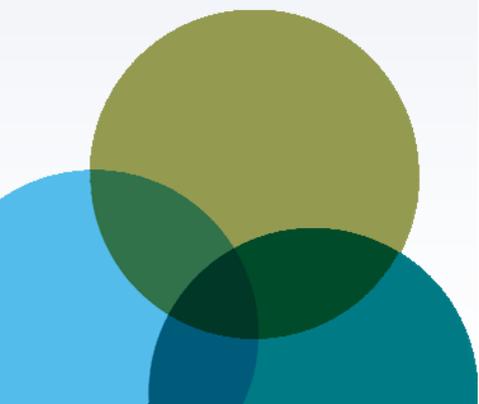
**BC Centre for Disease Control**  
AN AGENCY OF THE PROVINCIAL HEALTH SERVICES AUTHORITY

# Ethical Considerations Regarding Anonymous HIV Testing

David Unger, M.D.  
Mark Gilbert, M.D.  
Bobbi Brownrigg, R.N.

Clinical Prevention Services

September 2012



## Preamble

The purpose of this document is to conduct a comprehensive review of ethical issues related to an anonymous HIV testing pilot in British Columbia. These ethical issues have emerged through discussion with the Office of the Provincial Health Officer, as well as through discussion of the pilot with regional public health partners and managers and clinicians at sites interested in participating in the pilot. The document is framed as a series of questions and answers that address separate (although often related) ethical issues. While many of these issues are related we have tried where possible not to repeat points and hence there may be points or arguments in one section that apply in others, and it is the full picture raised by these discussions that is important to consider.

## Ethical questions

### **1. The published literature on the impact of anonymous HIV testing is sparse. Is it ethical to implement anonymous testing in BC as a pilot project, or does this need to be done as a research study?**

As anonymous HIV testing has been available in many jurisdictions and an accepted practice since the beginning of the HIV epidemic, the absence of evidence limits our ability to make a wholly evidence-based decision about the introduction of the pilot. In public health we have an ethical responsibility to gather and analyse information, and then to act on it. But we are also required (in the face of potential harm) to act with incomplete or nonexistent knowledge and data—that is, we are required to make judgment calls to act in the way that best serves the public. What we must do in this instance is determine whether the current harms associated with the existing HIV testing system are serious enough in BC to justify implementing a program in the absence of strong empirical evidence.

We do have good evidence in BC that individuals at risk of HIV delay or defer testing due to privacy concerns or specifically due to the lack of anonymous HIV testing 1-6, and the limited evidence on anonymous HIV testing does suggest that such individuals will access anonymous HIV testing and test at an early stage of infection.<sup>7</sup> As such, an argument for proceeding as a pilot program can be made. This needs to be done bearing in mind potential benefits and harms while constructing the pilot, analysis of the impact of the pilot project on the epidemic, and transparent dissemination of this analysis.

### **2. Is there enough evidence to support the conclusion that it is ethical to offer anonymous HIV testing?**

An ethical argument supporting offering anonymous testing would have to demonstrate that the potential benefits to society outweigh the potential harms. Intrinsic to this discussion is the assumption (based on evidence described above) that some at-risk individuals in BC who currently do not test or delay HIV testing will test through an anonymous HIV testing model, which will result in earlier diagnosis of HIV for those who are HIV positive.

Given this assumption, the following points are essential to understanding the potential benefits of anonymous HIV testing:

Individuals with undiagnosed HIV who do not test, or delay testing due to confidentiality concerns, are at risk of poor clinical outcomes due to untreated infection, and they place their

sexual or drug-using partners at ongoing risk of HIV. In a recent US modeling study, approximately half of all new infections were from the 20% of the population unaware of their HIV infection.<sup>8</sup>

With anonymous testing, individuals who test negative pose no risk of harm to others, but would have the benefit of an interaction with clinicians and pre/post test discussions which may either open the door to subsequent nominal testing or engagement in prevention behaviour.

With anonymous testing, individuals who test positive (who would otherwise not have tested at all, or have delayed testing) have the benefit of pre/post test discussions and may avail themselves of contact tracing and be linked to care and treatment (with accompanying public health benefit). Regardless of participation in these steps, the diagnosis of HIV alone will likely lead to behaviour change that prevents transmission to others.<sup>9</sup>

It is important to consider the potential harms of offering anonymous testing. There are several key general domains of concern over harms resulting from offering anonymous HIV testing. These are presented below followed by a discussion of the relevant considerations related to each.

a) **The concern over inability to act on a positive result.** As the provider will be unable to act on a positive result and contact an individual who has an anonymous positive HIV test result, there is the potential for missed opportunities for prevention due to a delay in receipt of results. This is most concerning in the scenario of an acute HIV infection, where immediate action has the potential for greatest reduction of risk of transmission to others.

While some evidence suggests that receipt of result does not differ for individuals testing anonymously or nominally<sup>7</sup>, it is to be expected that this scenario will occur with at best a delay of a few days and at worst the individual never returning for their result. The usual practice when contact information is known is to immediately contact the individual who has a positive result, and this is a particularly high priority for acute HIV infection and would be most concerning to providers in this scenario.

While as clinicians and in public health our goal is to prevent harm to others we must accept that there is a limit to what we can reasonably, ethically and legally do. Harms will occur to those we care for and those in the general community (whether known to us or not) regardless of our best wishes and intentions. There is also, and rightly, a portion of responsibility that is to be assigned to “those at risk” to make prudent decisions and manage their own health through safer sex and safer injection practices—it is not the sole responsibility of public health workers to ensure a completely safe environment. It is however our responsibility to strive to make a **safer** environment, and an anonymous testing program (as per the arguments supra), aims at doing good (at best), and aims at avoid harm(at least).

We must take care as clinicians and public health agencies not to limit potentially beneficial interventions simply out of fear of hypothetical slippery slopes. It is this courage that stands behind implementing harm reduction programs such as safer injection sites. In a free and just society people can, and do, make imprudent or inappropriate decisions and this may even include taking an anonymous (vs. nominal) HIV test. Our role and our obligation in this scenario is to bend our efforts to maximize opportunities for harm prevention to others—in the case of anonymous testing our obligation would be to exploit the opportunity in a pre-test

discussion to explore HIV risk and the possibility of HIV infection, and to give sound counsel about reducing risky behaviours.

b) **The concern that in the case of a positive HIV test result, anonymous HIV testing will result in reduced engagement, reduced scope of partner notification, and delayed referral to HIV medical care and treatment - and that this will further result in harm to society through reduced prevention of HIV transmission.** This is a hypothetical consequence of providers and public health staff being unable to contact individuals who have a positive result, or by allowing individuals to test anonymously who would otherwise test nominally or non-nominally.

Supporting partner notification and engagement in HIV care and treatment for individuals diagnosed with HIV are cornerstones of public health practice. The ultimate goal is that of improving individual health and reducing the risk of transmission to others. Arguments that anonymous testing will damage this objective are countered with the following considerations:

The literature does suggest that individuals who test anonymously may be less likely to notify partners and while more likely to be diagnosed at an early stage of infection may access care and treatment at a later stage, compared to individuals not testing anonymously.<sup>7</sup> While it is possible that this may be a result of reduced ability of providers and public health to follow-up with individuals with a positive result, it is important to acknowledge that this is also likely related to differences in characteristics of individuals who choose to test anonymously compared to those who do not (e.g., where concerns about privacy—which are a barrier to testing in the first place—also affect an individual’s willingness to participate in partner notification and progression to HIV related care and treatment).

The harmful impact on engagement in partner notification and referral to care (and thereby prevention of transmission to others) is predicated on an assumption that a person testing through an anonymous option will be less likely to cooperate with provider/public health-assisted partner notification and less likely to receive referral to care than would be the case if the same person tested nominally or non-nominally. To act on this assumption and not offer anonymous testing merely to facilitate a public health agenda (i.e. to follow-up each positive case and to persuade persons to engage in safer sex and injection activities) would, in fact, force people who desire anonymous testing to use other means to access care (this may include travel to other jurisdictions or countries, or procure home testing kits). To act on this assumption could drive the problem “underground”. HIV testing must be done in accordance with the realities of the current social situation. The patient is the one with the potential disease and the potential positive test, and public health staff or providers are doing what they can with the information they are provided, which is the extent of our moral obligation as a public health service to the people of BC. It is the client’s result—what this program proposes is placing more onus on the client to act on that result than the public health authority, and there is nothing that makes this morally illicit. In public health our priority should be to improve the health of the public and prepare for and control threats, not to be dogmatic about how programs should be implemented.

Citing concern over potential harms to individuals or society one may invoke the “harm principle”. The harm principle (after JS Mill) states that society is justified in intruding on the rights (in this case the confidentiality of information or the privacy of persons) of individuals when there is risk of harm to the greater public. But in attempting to apply this argument as justification for opposing anonymous testing the argument falls short. Invoking this argument

as a legitimate justification for not having an anonymous testing protocol would involve proving that there would be harm created to society by: a significant number of people testing positive anonymously that would have otherwise tested nominally **and** that some of these individuals undergoing anonymous testing would then refuse contact tracing and treatment **and** that said individuals would furthermore continue to spread infection. Only then would there be evidence of harm to the community; and only then could one invoke this “harm principle” argument. In the absence of evidence for clear harm, we are unaware of any ethical tenet which states that a public health organization must place ethical principles (such as confidentiality, respect for autonomy, or beneficence and non-maleficence of persons or society) in any particular priority sequence without first considering the nuances of the situation. In the absence of evidence of harm there is no ethical reason that confidentiality should not be considered a priority.

Finally, under the existing system it is possible to use fake names and provide false contact information such that there already exists a *de facto* form of anonymous testing, which is underground and unregulated. It would be better to have a controlled and regulated anonymous testing option that would not involve the anxiety and secretiveness involved in deploying such subterfuge to get tested. In a free and just society we should not place our citizens in a position where they have to lie or cheat to get health care they request or need.

**c) The concern that anonymous HIV testing will perpetuate stigma related to HIV and HIV testing by creating the perception / appearing to validate the concern that the current HIV testing system is not confidential, or that precautions related to getting an HIV diagnosis are required.** Anonymous testing, under this type of reading, is an example of “HIV exceptionalism”, which treats HIV testing differently from other testing for other infections and perpetuates stigma. As HIV is now a chronic, treatable disease and HIV testing is being normalized, public health messages related to an HIV diagnosis are shifting accordingly. Some would argue that offering anonymous HIV testing contradicts these positive messages.

It is important to consider this argument, as the desirable future state is for the elimination of stigma related to getting an HIV test, and reduction in perception of severity of HIV (from being perceived as a fatal, hopeless condition to a chronic infection which can be treated). However, the following is important to consider:

While HIV may be a treatable chronic disease and public attitudes about HIV are shifting with time, this does not change the fact that inaccurate beliefs and HIV stigma exists in society. By offering anonymous testing, we are not condoning this stigma or conceding any points, or giving inconsistent messages by playing to the uninformed beliefs of the population; we are merely listening to the concerns and beliefs in a non-judgmental way as a first step toward reducing stigma and these unfounded fears. We must meet people on their own terms and acknowledge their world view or belief system if we are to help to change them. People are entitled to their own beliefs and opinions and as health care workers we have an ethical duty to hear them out even if we disagree with them. A well run program of anonymous HIV testing with proper and informed pre and post-test discussions aimed at dispelling unfounded fears and clearing up misconceptions could go a long way toward improving stigmatization, and normalizing testing.

There are strong legal and ethical precedents which underpin similar programs—these use harm reduction as the justification. It is a fact that behaviours that lead to contracting HIV are,

at best not discussed in polite society (e.g. sexual practices), and at worst held in contempt by society (e.g. drug use). In situations like these, a tangle of ethical problems emerge that require innovative, novel, or nonconventional interventions. This often involves the notion of harm reduction—if a facile solution to a problem does not exist by a head on approach, at least it is best to reduce further harm through an oblique approach. Offering a variety of testing options to meet clients where they are willing/able to access the system is the best approach to take when trying to engage those who may not test or delay testing for HIV otherwise.

We conclude that the foregoing concerns are unfounded. In analyzing these concerns and with respect to assessing harms and benefits to society we further conclude that:

- i. there is evidence that the lack of anonymous HIV testing in BC poses a current risk to society (from undiagnosed individuals who delay or do not test for HIV),
- ii. that potential benefits are likely to be realized even if at a minimum an individual testing anonymously receives a diagnosis of HIV, and
- iii. that the potential harms are by and large hypothetical without evidence that such harm would occur.

On balance, the public health benefits of offering anonymous HIV testing outweigh the potential harms and this indeed complements the ethical argument in favour of anonymous testing. It is however, important to carefully consider how these potential harms may be mitigated (for example, targeted promotion in venues likely to reach individuals at risk of HIV and not general population messaging) and to include assessment of these outcomes where feasible in the evaluation.

**Given that all individuals who are HIV positive will need to be re-tested using their real name to access treatment (and the test result will be reported to public health), is it ethical or logical to offer anonymous testing in the first place?**

If we take it as a given that persons testing positive anonymously will have to be retested and access treatment only nominally then it, **at that point**, un masks the anonymity. But that does not undo the benefits of the anonymous testing program up until that point—that is, the benefits of getting an anonymous test remain intact up until that point so it is still a good thing. The evidence suggests that those who test anonymously will go on to get HIV treatment at which time the benefits of the initial anonymous HIV test are fully realized, and they will also have gained what they sought from anonymous testing, namely to get tested under their own terms and have control over their information and according to their own timeline. Even those who do not choose to go forward with retesting and treatment may still provide benefit to society in the form of safer sex and injection practices as a result of knowledge of HIV status. If anonymous testing was not available these people would not even have the opportunity to do good in society by adopting safer practices because they simply would not even know they were positive so in one sense anonymous testing can only do good but cannot do worse harm than not having a program.

It could be argued that having a person test positive and that person then not following up with nominally retesting and seeking treatment is somehow a failure of the public health system, but again, this scenario can get no worse than the person not knowing he or she is positive in the first place—anonymous testing at least opens the door to the possibility of good for society and could not be construed as malicious or harmful.

**1. For individuals testing anonymously, the testing provider may be aware of partners who need to be notified, or that there may be ongoing risk of transmission to others, yet due to the lack of contact and nominal information have no ability to take action. How should this be handled?**

There are two general scenarios in which this may occur, both of which are predicated on the notion that the identity of the person being tested is, in fact, known to the provider. In the first scenario, the provider receives a positive anonymous HIV test result and is aware that the individual who has not yet returned for his or her test result has partners that may be at continued risk of transmission. This poses a dilemma: should the provider ignore the spirit of anonymity and directly contact the individual to initiate provision of result and partner notification, or not act on the positive test result? One may consider that the positive result is the individual's result and not the public's result, **unless** clear evidence can be put forward that the person will then go out and cause harm to others (whereby the public gains stronger purchase on a claim to that result). This is difficult to establish and may favour not immediately taking action. In the second more troubling scenario, the provider becomes aware, through other means, that following the initial receipt of test result that the individual continues to pose a risk of transmission to others (either through indication that the individual will not change behaviour or disclose HIV status to partners at the time of receipt of result, or at a later date).

Taking action as a result of either scenario may undermine the integrity of the anonymous testing system, and care and trust in the health system due to not remaining committed to fulfilling its promise of anonymous testing. Changing our stance regarding anonymous testing, or changing our "script" in the final act by allowing exceptions whereby individuals are identified, would be damaging to the public's trust in our institution. As this scenario would justifiably cause moral distress to providers, it would be important to establish clear expectations and guidelines to providers providing the test (e.g., to consider whether the likelihood of this scenario may mean suggesting an individual see another provider if feasible).

One also needs to consider that in the first scenario, partner notification would only be done if the individual testing anonymous consents, which is no different than with testing nominally or non-nominally. That is, in our current system of non-nominal and even nominal testing there already exists a parallel problem in just what to do once the public health system is made aware of a new positive patient and that person's results are reported to the MHO. In the current system patients must voluntarily provide contact information, and sometimes they refuse. There is no less harm done by the current system than would be done in a system that permits anonymous testing.

This situation where the testing provider actually knows the client would likely occur if anonymous HIV testing were available in a small community, either geographic or social, where an individual may not have another choice of provider. It could be argued that an anonymous testing option must be provided for all persons in the province but this is not really the case with all health programs. If one lives in a small town one does not have **immediate** access to many of the health care goods offered in a large centre (such as a renal transplant team, public lectures on health care topics, healthy heart programs etc) and that is unavoidable. If anonymous HIV testing were to be offered in a small community and individuals would also need to be willing to seek a provider known to them to access anonymous HIV testing, these concerns may need to be addressed in pre-test discussions.

- 2. When an individual who has a positive anonymous test subsequently tests nominally as part of access to care, the second test result will be reported to public health for follow-up as part of routine practice. When the provider or public health staff follow-up with the individual, the individual may reveal that they previously had a positive anonymous HIV test in BC. This information would be documented and then used to exclude the individual from surveillance reporting so that there is no double-counting. Is it ethical to collect and document this information as this then creates a documentation of a previous anonymous test linked to an individual, as this could lead to potential harm (e.g., in the scenario of documents being subpoenaed as part of a criminal investigation into HIV non-disclosure)?*

While ensuring that surveillance data is of highest possible quality is important, it is not sufficient to override the potential public good of interventions. There are other examples where public health programs have affected surveillance data quality; for example, with the known impact of HIV reportability rendering historical analysis of HIV surveillance trends during the pre/post period difficult, or where Point-of-Care HIV testing means that we are no longer able to accurately identify repeat HIV tests because data is only available in aggregate.

We do need to stick to our commitments and adhere to the principles of anonymous testing, so identifiable information should not be linked to an anonymous HIV test result after the fact. That being said, however, in this scenario it would be possible and entirely licit to document that a previous anonymous HIV test was performed if the individual voluntarily provides this information and agrees that it could be documented on the case report form. We can also minimize potential harms by not attempting to link a nominal test result to a specific earlier HIV test result, as the minimal information that is needed for surveillance purposes is the knowledge that a previous positive HIV test was done in BC (not what site or when it occurred).

## References

1. Kanters et al. Survey and Dried Blood Spot results: Vancouver Site, M-Track Surveillance System, 2010.
2. Wardman et al. HIV/AIDS: Testing and Risk Behaviors Among BC's rural Aboriginal Population. *Int J Circumpolar Health*, 2006.
3. Goldenberg et al. Barriers to STI testing among youth in a Canadian oil and gas community. *Health and Place*, 2008.
4. Shoveller et al. Youth's experiences with STI testing in four communities in BC, Canada. *Sexually Transmitted Infections*, 2009.
5. Miller et al. The diagnosis and care of HIV infection in Canadian Aboriginal Youth, 2008.
6. BCCDC. Avoidance of HIV Testing Due to Lack of Anonymous HIV Test Option in BC, 2012.
7. Salway-Hottes, Gilbert. *Anonymous HIV Testing: Evidence Review and Environmental Scan*, 2012.
8. Hall et al. HIV transmission rates from persons living with HIV who are aware and unaware of their infection. *AIDS*, 2012.
9. Marks et al. Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: Implications for HIV Prevention Programs. *JAIDS*, 2005.