

CREATING ENVIRONMENTS THAT RESPECT THE PRIVACY AND CONFIDENTIALITY OF ABORIGINAL PEOPLE LIVING WITH HIV/AIDS

**A Resource for Aboriginal HIV/AIDS
Service Organizations and other Organizations
that Provide Services for Aboriginal People
living with HIV/AIDS**

A Publication of the Canadian Aboriginal AIDS Network

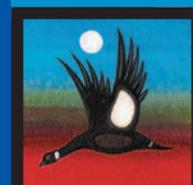


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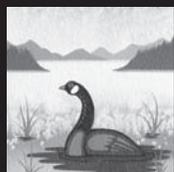
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Declaration of rights for Aboriginal people living with HIV/AIDS

The following declaration is based on "Rights of a Native Person Living with HIV/AIDS", originally developed by the Atlantic First Nations AIDS Task Force (now known as Healing Our Nations). It was presented in a joint Canadian HIV/AIDS Legal Network and Canadian Aboriginal AIDS Network Information Workshop at the Canadian Aboriginal AIDS Network Skills Building Symposium held in Vancouver on September 27, 2001.

1. We have the right to privacy and confidentiality regarding our HIV status.
2. We have the right to support from our community, family, partners and individuals.
3. We have the right to access spiritual teachers and participate in ceremonies as children of the Creator.
4. We have the right to be given quality health care as guaranteed in the Treaties of Canada and those given to citizens of Canada.
5. We have the right to engage in and continue intimate and sexual relationships ensuring risks will be addressed through safer-sex awareness, practices and respect.
6. We have the right to live a free and dignified life, including having the right to meet basic human needs such as decent housing and income security, and assistance to meet special needs.
7. We have the right to access all services and programs, including treatment centres, counselling services, education, and child and family related services such as support for our children and pregnancy guidance.
8. We have the right not to be condemned, judged or forgiven as to how we acquire this disease.
9. We retain our right to be gay, straight, two-spirited, lesbian, bisexual or transgendered. This should not now or ever determine the quality of our care.
10. We have the right to be provided addiction treatment without disclosing our status and the right to access treatment for our disease while in an addiction treatment program.
11. We have the right to freely choose where we live.
12. We have the right to use legal avenues to protect against discrimination.
13. We have the right to medical transportation to and from medical facilities without fear of discrimination.
14. We have the right to rely on Aboriginal approaches to healing first and as an alternative or complement to our care.



15. We have the right to expect our service providers to be sensitive and knowledgeable about HIV/AIDS and act in the best interests of all living with or affected by HIV/AIDS.

16. We have the right to live.

Key words, Phrases & Acronyms

AASO

Aboriginal AIDS Service Organization. For the purposes of this document, the term AASO may also include mainstream ASOs who have a significant proportion of Aboriginal clients.

ASO

AIDS Service Organization. A health association, agency or organization that is actively involved with the prevention and treatment of HIV/AIDS.

Aboriginal

Indigenous peoples in Canada, including Inuit, Métis and First Nations, who are status or non-status, on or off-reserve.

Aboriginal Community

Refers to a group of Aboriginal people residing in a single locality and/or united through shared experiences. Such communities may arise in reserves, remote settlements, or rural or urban areas. The term may also be used generally to refer to all Aboriginal people living in Canada.

AIDS

Acquired Immune Deficiency Syndrome. AIDS is a clinical diagnosis that can only be given by a doctor. It occurs when someone has tested positive for HIV and has at least one opportunistic infection (an infection that the body cannot fight off because of a weakened immune system).

APHA

Aboriginal Person Living with HIV/AIDS.

CBO

Community-Based Organization. This includes ASOs, AASOs, community health care providers, and other not-for-profit organizations.

Community

A group of people connected to each other based on where they live, the work they do, their ethnic background, the way they live, etc.

Confidentiality

A duty that is imposed on certain people and organizations as one way of protecting a person's privacy. There is both a legal duty of confidentiality and an ethical duty of confidentiality. From the perspective of people living with HIV/AIDS, the most important duty is the one placed on certain people and organizations to keep personal health information confidential.



Disclosure

Telling someone something private. HIV disclosure refers to the disclosure of a person's HIV status.

HIV

Human Immunodeficiency Virus. HIV is a virus that needs the human body to live. It attacks the body's immune system and does not allow the immune system to fight off diseases and infections the way it is supposed to. HIV can only be transmitted through blood or other bodily fluids. Tears, sweat and saliva do not contain enough of the virus to be contagious.

Informed Consent

Type of consent that means that a person submits knowingly to a procedure, possessing all of the information necessary to make an informed decision.

Legislation

Legislation is written law. It includes acts, regulations and by-laws.

OCAP

Ownership, Control, Access and Possession. Refers to the status of information and programs intended to benefit Aboriginal people in Canada and the notion that these programs should be owned, controlled, accessed and possessed by Aboriginal People for Aboriginal people. The Aboriginal HIV/AIDS Privacy and Confidentiality Initiative is committed to the principles of OCAP.

PHA

Person Living with HIV/AIDS.

Policy

A guiding principle or plan of action agreed to by a group of people with the power to carry it out and enforce it.

Privacy

The ability individuals have to stop information about themselves from becoming known to people other than those whom they choose to give the information.

Stigma

Something that causes shame, like a mark or characteristic. Stigma is closely associated with discrimination.

Street-Involved

A person who lives on the streets, is homeless, or works on the streets.

Treatment(s)

Prescribed medical therapy.

Two-Spirit or Two-Spirited

A generic term used by some Aboriginal people to describe, from a cultural perspective, people who are known in mainstream as either gay, lesbian, bisexual or inter-sexed/transgendered.



1. Introduction

When Aboriginal People living with HIV/AIDS (APHAs) think of “privacy”, a number of different thoughts come to mind. There is the idea of privacy in *HIV testing*. Many people want to be tested anonymously, without anyone else knowing their results or their name. There are privacy issues which come up when accessing HIV/AIDS service organizations or other service providers. APHAs should be able to receive information, services and support from these organizations without the whole community finding out. Privacy is an important factor in counselling. APHAs want to be able to open up to counsellors without having anything they say leave the room. Privacy issues often arise in the workplace.

APHAs should be able to access medical benefits, take sick time off work, and have any special needs accommodated without all of their colleagues finding out they are HIV positive. Many APHAs expect a certain amount of privacy in their *personal relationships*. They would like to be able to reveal their HIV status to a boyfriend or girlfriend without having them tell everyone in town. Community leaders are expected to respect peoples’ privacy. APHAs want to be able to speak to an Elder or spiritual advisor about their problems without having the whole community gossiping about them.

Privacy is an especially important concern when accessing *medical services*. APHAs do not want to have their doctors talking to them in hospital hallways and they do not expect to find third parties in the examination room during routine check ups. Privacy issues may arise even when going to the pharmacy. APHAs want to be able to talk to the pharmacist without having the next three people in line listening to their conversation. Privacy is also an important consideration within the HIV/AIDS movement itself. APHAs want to be able to contribute to the movement (e.g. attend functions, give speeches) without having others assume that they are “out” in every part of their lives, and they do not expect to find their names and personal information posted on the Internet.

In some of these situations there are laws in place which are intended to help protect APHAs’ privacy. In many of these situations there are not. Sometimes the law may work to actually to limit an APHA’s privacy, such as requiring a health official to report a positive HIV diagnosis and do contact tracing. In other situations, the law may actually impose a duty upon APHAs themselves to disclose their HIV status to someone else (e.g. before engaging in certain activities which may put others at risk). Even when there are laws in place to protect privacy rights – and APHAs have the means to access them – no one can ever restore a person’s privacy once it has been lost. This is one of the main reasons why the protection of privacy is such an important issue for Aboriginal people living with HIV/AIDS.

When an APHA’s privacy has been compromised, the consequences go well beyond the individual. The harmful effects can be felt by an entire community. For example, other community members will be more reluctant to seek HIV testing and counselling if they believe that their HIV status may be disclosed without their consent to friends, family, employers, insurance companies or the government. If fewer people find out that they are HIV positive through testing, the risk of further HIV transmission is increased. The belief that there is a lack of privacy of health information can create a situation where people who need medical treatment or other services may not seek it. This is particularly relevant to many Aboriginal peoples who already have a historical mistrust of institutions such as hospitals and other medical establishments.



Having people know that you are HIV positive can open the door to stigma and discrimination in virtually every part of your personal and professional life. People living with HIV/AIDS have lost their jobs, been deprived of housing, felt ostracised in their communities and had their social relationships compromised, all as a result of the disclosure of their health information without their consent. Despite more than two decades of research and public education about HIV/AIDS, ignorance and stereotypes continue to shape much of society's reaction to APHAs. It can be difficult to predict how people will react, or how someone's life may change, if and when their HIV status becomes known by others. In light of the potential consequences and possible life changes that may follow, it should be every APHA's right to control how, where, when and to whom the disclosure of their HIV status is to take place.

The following report is based on a year's worth of research and interviews by the Canadian Aboriginal AIDS Network, in consultation with a National Steering Committee. Interview participants included members of the HIV/AIDS community (APHAs and front line workers), legal professionals and Elders.

While it focuses on Aboriginal HIV/AIDS Service Organizations, or other organizations that serve APHAs, it by no means suggests these are the only places where violations occur of one's privacy and confidentiality. Indeed, even medical service agencies, who ought to be more aware and protective of personal information, may be among those service providers who fail to respect the privacy of APHAs. Furthermore, even APHAs themselves may knowingly or unknowingly breach the privacy of other APHAs by speaking to other HIV-positive people about who attended the CAAN APHA Caucus or other APHA Gatherings it holds from time to time. This resource opted to focus on AASOs or other service agencies where it is assumed that most APHAs might be accessing services. Certainly the information contained in this resource can be used by anyone or any agency to create environments that respect the privacy and confidentiality of APHAs.



2. What is “Privacy”?

We use a lot of words without thinking about what we mean by them. ‘Privacy’ is an abstract and contentious notion that lacks a clear, universally accepted definition.

People tend to think of privacy as some kind of right. The concept of a ‘right’ is a problematical way to start, because saying “you have a right” seems to suggest some kind of absolute standard. Plus it is very easy to get confused between what we call “legal rights” on the one hand, and “natural” or “moral” rights, on the other. It turns out to be much more useful to think about privacy as one kind of “thing” (among many kinds of things) that people like to have lots of.

From a legal perspective, privacy turns out not to be a single interest, but rather has several dimensions¹:

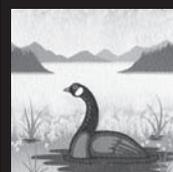
- **privacy of the person**, sometimes referred to as ‘bodily privacy’. This is concerned with the integrity of the individual’s body. Issues include compulsory immunisation, blood transfusion without consent, compulsory provision of samples of body fluids and body tissue, and compulsory sterilisation;
- **privacy of personal behaviour**. This relates to all aspects of behaviour, but especially to sensitive matters, such as sexual preferences and habits, political activities and religious practices, both in private and in public places. It includes what is sometimes referred to as ‘media privacy’;
- **privacy of personal communications**. Individuals claim an interest in being able to communicate among themselves, using various media, without routine monitoring of their communications by other persons or organisations. This includes what is sometimes referred to as ‘interception privacy’; and
- **privacy of personal data**. Individuals claim that data about themselves should not be automatically available to other individuals and organisations, and that, even where data is possessed by another party, the individual must be able to exercise a substantial degree of control over that data and its use. This is sometimes referred to as ‘data privacy’ and ‘information privacy’.

When APHAs talk about “privacy”, they are often referring to privacy of personal data, or “informational privacy”. They tend to talk of “privacy” in terms of the ability to stop information about themselves from becoming known to people other than those whom they choose to give the information.

Privacy Protection

Privacy as an interest has to be balanced against many other, often competing, interests²:

- the privacy interests of one person or category of people may conflict with some other interest of their own, and the two may have to be traded off (e.g. privacy against access to credit, or quality of health care);



- the privacy interest of one person or category of people may conflict with the privacy interests of another person, or another category of people (e.g. health care information that is relevant to multiple members of a family); and
- the privacy interest of one person or category of people may conflict with other interests of another person, category of people, organisation, or society as a whole (e.g. creditors, an insurer, and protection of the public against serious diseases).

Therefore when we speak of “Privacy Protection”, we are really talking about a process of finding appropriate balances between privacy and multiple competing interests.

Is Privacy a “Right”?

Privacy is often described as a “right”, at least in the sense that it is recognized and/or “read in” to constitutional and quasi-constitutional documents. In terms of an individual’s interaction with the state, we do have a right to privacy, but the notion of “privacy” can mean many different things (e.g. your personal physical integrity, your residence, information relating to individuals, etc.).

Unfortunately, it can be somewhat problematic to tell APHAs that they have a “right” to privacy. For one thing, very few rights are absolute rights. Most rights have to be balanced against other competing interests (e.g. other peoples’ rights, policy considerations, etc.). Also, calling something a “right” brings to mind the notion of an enforceable entitlement. However, our laws protect privacy in a very limited way. In many situations involving a breach of privacy, APHAs do not have any enforceable entitlements. For example, if a scorned ex-partner decides to maliciously reveal your HIV status on an Internet chat group, your privacy has certainly been compromised, but there is very little that you can do about it legally.

Similarly, if individuals in a small community are spreading gossip and rumours about your HIV status, your privacy may be compromised but the law may not offer you much protection. In these situations, to tell APHAs that they have a “right to privacy” can be quite misleading.

Furthermore, although “privacy” is recognized under both the constitution and international human rights law, the protection can be quite limited in scope. The Canadian constitution, for example, mainly refers to “bodily privacy” (e.g. protection against such things as compulsory immunisation, blood transfusions without consent, taking samples of body fluids and body tissue without consent, forced sterilization, etc.), and not “informational privacy” (privacy of personal data), which is what APHAs usually mean when they talk about privacy protection. Also, although privacy is described as an international human right, the scope of this right and the mechanisms for enforcement is also limited.

Finally, it has been suggested that “privacy”, at least in terms of information relating to health, is not even a typical Aboriginal traditional or cultural value. In a traditional sense, Aboriginal communities needed to know when someone was ill because the whole community was responsible for caring for the sick.



What is the Difference between “Privacy” and “Confidentiality”?

People are often confused by the related terms “privacy” and “confidentiality”. Another related term, the rule of “privilege”, can also be a source of confusion. In *Privacy Protection and the Disclosure of Health Information*³, the terms are distinguished as follows:

People living with HIV/AIDS have a **right to privacy** regarding their health information. Health professionals, and some other people who provide services to people living with HIV/AIDS, owe a duty to people living with HIV/AIDS to keep their health information confidential. This duty is called the **duty of confidentiality**. The **rule of privilege** is a rule of evidence. In some circumstances, it can prevent a person who owes a duty of confidentiality to a person living with HIV/AIDS from having to disclose that person’s health information in a court case. [Emphasis Added]

Simply stated, “confidentiality” is a duty that is imposed on certain people and organizations as one way of protecting a person’s privacy. There is both a legal duty of confidentiality and an ethical duty of confidentiality. From the perspective of people living with HIV/AIDS, the most important duty is the one placed on certain people and organizations to keep personal health information confidential.



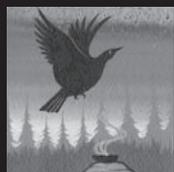
3. Breach of Privacy

What Kind of Privacy & Confidentiality Breaches do APHAs Continue to Experience?

APHAs can experience many different types of privacy challenges in virtually every part of their lives. During the interview phase of the Aboriginal HIV/AIDS Privacy and Confidentiality Initiative, participants discussed numerous examples of unwanted disclosure of HIV status and other privacy breaches, including:

- ASOs and AASOs
- HIV/AIDS testing
- Health care providers and pharmacists
- Social services, counsellors and community workers
- Prison staff and fellow inmates
- Workplace related matters
- Criminal disclosure
- Police
- Researchers
- Seemingly harmless policies and procedures
- Remaining anonymous in small communities
- Casual infringement of privacy
- Friends, family, acquaintances and other community level experiences

The above list is by no means exhaustive. We were surprised by both the volume and variety of privacy breaches our interview participants experienced. Faced with so many different categories of privacy breaches, we had to decide where we should focus our study and where we could make the biggest impact. Clearly, the biggest complaint coming from the APHAs during our interviews involved the breaches of privacy they experienced by ASOs and AASOs. We therefore decided to make this topic the main focus of our report. Also included but not listed are APHAs themselves who at times assume another APHA is open about their HIV status or simply talk with other APHAs about who may have been at a meeting for APHAs.



4. ASOs and AASOs

AASO staff and volunteers generally owe clients both a legal duty and an ethical duty to maintain the confidentiality of the client's personal information, including HIV status. For example, there is a common law duty of confidentiality owed by staff, volunteers and ASOs to clients to maintain the confidentiality of clients' personal information.⁴ Staff who are members of regulated professions (like registered nurses, social workers or psychologists) also have a statutory duty (i.e. written in legislation) to maintain client confidentiality. This legal duty of confidentiality is usually found in the provincial and territorial acts and regulations that govern the profession. Furthermore, AASOs often codify their confidentiality obligations in their organization's policies, procedures and guidelines, and strive to make all new staff and volunteers understand how easily confidentiality can be breached and has been breached in the past.

It is important to note, however, that an AASO's duty of confidentiality is not absolute: there are certain circumstances under which AASO members are not only allowed, but may be expected to breach a clients' confidentiality. Privacy is about balancing of rights and sometimes AASOs find themselves in the situation where they have to consider the fact that if they keep confidentiality, there may be serious harm to someone else they have a duty of care to and therefore they may open themselves up to liability for failing to disclose.⁵ Other times disclosure may be required by law or by order of a court of competent jurisdiction.

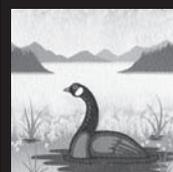
These scenarios, however, are the exceptions. The vast majority of privacy breaches identified during the interviews, including those identified in this report, are the types of breaches that do not fall within these two categories. As such, they are the types of breaches that AASOs must strive to avoid.

AASO Privacy Breaches

When AASOs do breach an APHA's privacy, it is usually not done by gossiping or for any malicious purpose. It is usually an act of inadvertent disclosure. Sometimes the overworked environment of many AASOs means that privacy concerns may not receive as much attention as is required. Sometimes privacy and confidentiality is simply not the major issue on AASOs' and clients' minds (e.g. if a client has nowhere to live, cannot obtain healthy food, has no money, no health card etc). Other times, it may be an issue of inadequate staff training or simply not being aware that a problem exists until it is too late.

When it comes to confidentiality, there tends to be more trust in the medical community and less in AASOs and other community based organizations. Medical workers have highly defined codes of conduct and upon a breach of privacy there are established complaints mechanisms in place. When it comes to AASOs, oftentimes all you have is your trust in the workers to keep your information confidential and to handle your information responsibly. The AASOs owe a large part of their existence to maintaining the trust of a community. What makes the breach of privacy so great is that it is really a breach of trust. A lack of faith in the confidentiality of the AASO, therefore, means a threat to the organization's very existence.

Below we have identified the most frequent AASO privacy issues that came up during the interviews.



It is important to stress that the goal here is not to point fingers or lay blame to those AASOs who have made these mistakes in the past. In fact, it has been suggested that almost every AASO has come across at least some of these privacy issues at one time or another. Our goal here is simply to show how easy it has been to breach (often unknowingly) an APHA's confidentiality regarding their HIV status. At the very least, some of these actions have drawn attention to an APHA client, allowing other people to draw inferences as to whether or not they were HIV-positive.



5. Most frequent AASO privacy issues that came up during the interviews

Issue # 1

Assuming APHAs to be Open in Every Part of their Lives

This is a common theme whenever APHAs have a lot of contact with an AASO. It also comes up as the biggest privacy complaint regarding attending conferences or other HIV/AIDS related events. The problem involves both AASO clients and HIV-positive staff members.

For AASO clients, the rules are clear. The client should be the one to decide when, to whom and how much of their health situation to disclose. They should have control throughout the entire process and any consent to disclose should only be given after they are made to fully understand the implications.

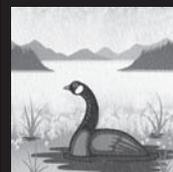
For HIV-positive staff members, the problem is a little more difficult to control. Interview participants indicated that a common problem is that other people will wrongly assume that if certain APHAs are open about their HIV status on the job, then they are open about their status in every part of their lives. For example, one APHA was working at an information booth in an Aboriginal community when he was introduced to a local leader by a fellow worker as “this is PAT who has HIV”. Although the APHA was comfortable talking about his status, he still let the offending individual know that the introduction was not appropriate. Another example is when APHAs are involved in the production of AASO resources.

APHA input is an essential component to giving legitimacy to this type of work. However, sometimes co-workers may forget that when the APHA freely discusses his/her experiences within the walls of the AASO, this in no way means that the APHA consents to being identified as being HIV-positive in any published document, workshop, gathering or discussions with other involved parties. In as much as possible, AASOs should allow the APHA to control the degree of disclosure he or she is comfortable with. Sometimes, however, the nature of the working position does not allow for this. For example, if an APHA is hired as an APHA advocate or other position where disclosure may be a necessary part of the job, then they may be expected to be public about their status. However, this must be fully explained to the staff member before they take on the position and they must be fully aware that being open about their status is an essential component of the job.

Issue #2

Talking in Environments Where Others Can Overhear

Another common problem identified during the interviews was AASO staff talking about HIV status in environments where others can overhear. This complaint is by no means confined to AASOs: interview participants made the same complaint about hospitals, clinics, pharmacies, and other organizations dealing with their confidential health information.



Although this problem was sometimes associated with the carelessness of staff, other times participants pointed to the physical set up of the AASO or organization itself. Some AASOs can only afford to be set up in one large room where everyone (staff, clients, volunteers) is within earshot of everyone else. Other organizations have shared phones or only semi-private conference rooms. Thus telephone interviews, private discussions and in-person meetings are overheard by other people in the office. Although funding realities often mean that sharing office space is unavoidable, AASOs should strive to have at least one isolated phone and conference area where private discussions can take place outside of earshot.

A related issue to the above is that sometimes clients themselves do not think about their own privacy while at the AASO. Clients may be talking really loudly about their HIV status or other health information, falsely assuming that everyone at the AASO is responsible and required to know about these things. Entering these organizations sometimes gives APHAs a false sense of security in that they will not be “outed” in the community. They do not understand that they are disclosing their status to other clients and everyone within earshot when they do not have to.

Issue #3

Letterheads, Messages and Mailouts

Something as simple as a letterhead may lead to the unwanted disclosure of someone’s HIV status, or at the very least may cause others to make this assumption. For example, one APHA spoke of receiving a letter from a well known ASO with the ASO’s letterhead on the envelope. Unfortunately, the letter was delivered to the wrong apartment, and a neighbor placed it where all the tenants could see it (this was where they usually placed incorrectly delivered mail). By the time the APHA picked up her letter, everyone in the building could have seen her name associated with the ASO. Although some neighbors may have thought that the letter was merely a call for donations, the APHA indicated how unsettling it would be if - due to her build, physical characteristics or lifestyle - her neighbors already suspected that she was HIV-positive and this was the confirmation. It is a good practice when APHAs become part of a mailing list to ask how the letters should be addressed and how they are to be delivered.

Some AASOs already protect their clients from this type of scenario by having two different stamps for their mail, one with the organization’s name (for business mail) and another with only the street address (for APHA mail). This simple precaution could save a lot of unnecessary grief to their clients.

Another similar problem is leaving phone messages by identifying yourself as a member of an AASO. Some organizations try to avoid this by only leaving the organization’s acronym, but this does not offer much protection. For example, when trying to reach an incarcerated APHA, a prison’s contact person may try to get detailed information about the caller and ask what organization they work for. Identifying yourself with your AASO may be enough to start the institution’s rumour mill going. It may be much wiser to identify yourself as a friend or an acquaintance and let the inmate decide how you are to be identified to staff. A further problem when dealing with inmates is the confidentiality of mailouts. Incarcerated APHAs have been quick to point out that any information sent to them will be seen by many eyes before it makes it to their cell. Sending a number of HIV/AIDS pamphlets and manuals to an inmate can easily lead to everyone in the institution knowing or suspecting that they



are HIV-positive. The confidentiality of mailouts is also a concern when dealing with youth still living with their parents.

Issue #4

Breaching Privacy by Seemingly Harmless Offerings

An APHA's privacy can sometimes be compromised by what seem to be harmless policies by the AASO. Some AASO "give-aways" (or promotional items) clearly identifying the organization are an example of a situation where privacy may end up being compromised without any malicious intent or negligence. For example, conference bags and clothing articles carrying an AASO's logo or an HIV/AIDS message can act as an advertisement that an APHA uses the organization's services. When people of limited means are given such items, they will use them, even if it may identify them as HIV-positive to others.

Some AASOs have countered this problem by providing creatively designed "give-aways" that do not have any easily identifiable HIV/AIDS information. For example, "give-aways" that only display some meaningful Aboriginal art, or luggage tags and pill boxes that have the organization's logo very discretely placed, are excellent ways of giving something to clients without turning them into walking advertisements for HIV/AIDS services.

Issue #5

Picking up Medication

In terms of picking up HIV/AIDS medication, many street-involved people use a street outreach nurse or front-line organization, as opposed to the pharmacy. These are environments that are described by interview participants as "HIV-friendly" and tend to have good privacy safeguards, although privacy breaches do still occur. As with other medical facilities, a common complaint is trying to protect your privacy while speaking with the person at the counter to pick up meds. Oftentimes there are others around who can hear every word, including talk of someone's HIV status.

In one inner-city community, the APHAs interviewed discussed how they all pick up their medication at the same location. This location gives the HIV/AIDS medication in a recognizable bag. They say that when they see others with this certain bag (and of a certain size), they can tell right away where they came from and what they have in it.

Issue #6

Office Gossip

Another frequently mentioned concern is about the amount of gossip that takes place within and among AASOs. Whereas the Aboriginal community in a certain area may be relatively small, the Aboriginal HIV/AIDS community is one that always seems to be on a "first-name basis". Although it stretches nation-wide, it often seems like everybody within the movement knows everybody else.



As such, within the AASOs, staff members and volunteers will often talk amongst themselves and ask each other “is that person positive”? Although this type of gossip seems to be unavoidable within any organization where people work closely with each other, what must be remembered is that AASO staff members are expected to follow a higher standard when dealing with APHAs.

When it comes to maintaining the confidentiality of APHAs, in many situations AASOs are among the only places that APHAs can turn to with complete trust and confidence. These APHAs should be able to access services without having everyone talk about them as soon as they leave. A guiding principle when working within AASOs must always be that information is to be shared only on a “need to know basis”. To do otherwise creates an office climate void of professionalism and an AASO that betrays the trust of its people.

Issue #7

Intentional Privacy Breaches - “For the Client’s Own Good”

In rare situations, a breach of confidentiality at a front line organization can also be intentional in order to help an APHA and to ensure that he/she gets the proper access to treatment. For example, in one situation a front line worker took it upon himself to go to a community health nurse and say “do you know this person is not on “meds” with an extremely low CD4 count?” Especially when dealing with a certain populations (e.g. highly addicted to drugs, high risk activities, self-destructive tendencies) front line workers may be tempted to compromise the client’s privacy in order to help them.

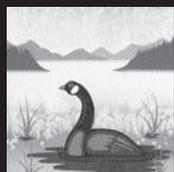
At one front line organization in a high drug area with many social problems, when these types of breaches did occur, and the supervisors found out about them, those involved were not penalized for them. This may be due to the fact that (a) nobody complained about the breach, and (b) the organization serviced a street-involved population that tended to rely a great deal on social services for their well being.

Issue #8

Providing Personal Information

If an APHA wants the services that an AASO has to offer, then to a certain extent the APHA is going to have to disclose his/her HIV status to someone. There is really no way around this. But the number of people to whom the APHA must disclose, and the AASOs commitment to addressing privacy concerns, is where the problem lies.

For example, for scholarship applications and other AASO documents, APHAs are asked to provide their personal information, including their HIV status. Also, some APHAs take part in confidential interviews where their data is transcribed and kept on file. In both cases, some APHAs indicated that they would like to have some kind of assurance that the information will be (a) stored on a temporary basis, (b) destroyed after a certain amount of time, and (c) that their confidentiality will be guaranteed.



Some AASOs will only use client codes on all of their forms in order to ensure maximum confidentiality for certain types of services. Also, many researchers will make these points clear before conducting their interviews. In all cases, the APHAs should be made aware of how long their identifiable information will be kept on file, and what safety precautions the AASO uses to ensure their confidentiality.

Issue #9

The Use of Volunteers

Volunteers are another identified problem area when it comes to privacy concerns. Some interview participants indicated that volunteers do not have the same amount to lose in the case of a privacy breach and they often do not have the same level of training and information as paid employees.

Some AASOs have addressed this issue by drafting a separate confidentiality agreement form just for volunteers, clearly outlining their privacy responsibilities. They also take extra care to ensure that the volunteer knows all of the privacy procedures and expectations in detail, as opposed to simply making them sign a privacy agreement that they may or may not have fully read or appreciated.

Issue #10

Understand What is Being Signed

AASOs often draft confidentiality agreements for clients to sign. Similarly, before participating in any study, activity or project, APHAs are often asked to sign forms indicating that they fully understand what they are getting into. We cannot stress enough that it is the responsibility of the AASO to make sure that APHAs understand what they are signing. On a number of occasions, interview participants said that after having their HIV status revealed or their privacy otherwise compromised, they realized that they did sign some kind of privacy waiver or document, but it was not explained to them exactly what they were agreeing to.

This issue is explored below, under “Becoming an HIV/AIDS Poster Person”. Especially when dealing with populations where language or reading skills may be a factor, special care should be taken to ensure that people really understand what they are signing. Asking the individual a few probing questions and clarifying any ambiguous language or difficult terms are some of the ways this can be done.

AASO staff members are also typically required to sign confidentiality agreements acknowledging that they understand their organization’s privacy policy and their obligations to their clients. It is important to note that an AASO may have the greatest, most articulate and most progressive privacy policy in Canada, but if the employees do not take the time to read it and especially understand it, then it has been drafted in vain. Making sure an AASO’s employees understand the policy can be just as important as the policy itself.



Issue #11

Overworked Atmosphere

Privacy breaches by AASOs happen a lot more often than they should, but one must keep in mind the whole atmosphere of working at some front line organizations. An overworked atmosphere is a breeding-ground for privacy breaches. When combining the stress and workload many front line workers face, shortcuts are sometimes taken (e.g. assuming a community nurse/counsellor knows a client is open about his/her HIV status, not properly securing confidential data, losing track of files in the case of staff departures, etc.).

Although we do not want to give too much credence to the overworked/underfunded explanation for privacy breaches, these practices should be taken in context. When taking on duties, planning activities and allocating funds, the risks associated with overburdening staff must be acknowledged.

Issue #12

Adequate Privacy Training of Staff

Certain AASO staff members (e.g. counsellors, trained researchers) are expected “to just know” about the importance of protecting the privacy of APHAs in every way possible. Others are expected to know this through common sense. However, there are people (e.g. new staff, volunteers) that must be given much more detailed privacy instructions than everyone else. Although different staff members may have different amounts of responsibility within the office, everybody working within the AASO (from executive director to office cleaner) will be exposed to APHAs and to a certain amount of private information. It is up to the AASO to determine the appropriate level of privacy training per individual.

Simply having all staff read the organization’s guidelines and then sign a form is not enough in every situation. There is no “one size fits all” when it comes to privacy training. Health information is recognized as one of the most sensitive classes of personal information and should be afforded a high degree of protection. It is up to the AASO to ensure that all staff members fully understand their privacy obligations and have received individual training for the responsibility they will have.

Issue #13

The Location of the AASO

Something as basic as where the AASO is located can cause privacy challenges for those APHAs who use its services. Some AASOs are extremely committed to protecting their clients’ privacy. They take every reasonable precaution and are always on the lookout for ways to improve their privacy protections and ensure the anonymity of all of their clients. However, due to the physical location of the AASO, as soon as people see someone walking into their office to access services, then the assumption is that the person is HIV-positive. One AASO which has very well designed privacy procedures indicated that this was the hardest part of ensuring the privacy of its clients.



This issue is especially troubling for youth or inhabitants of communities where “everyone knows everyone”. Interview participants suggested a number of ways to decrease the implications of being spotted. Recommendations included making sure the AASO was not in an independent building (e.g. one APHA was spotted by acquaintances in the parking lot of an HIV clinic), or perhaps combining all sorts of services in the same building (e.g. having a used/free clothing store).

Issue #14

Different Organizations Offer Differing Levels of Privacy Protection

Different organizations will have different levels of privacy protections for their clients. Some individual staff members and organizations will go to extraordinary lengths to protect their clients’ privacy. For example, one professional involved in the HIV/AIDS field will not even say “hello” to HIV-positive people on the street. He explained that as someone who is well known for his work in the HIV/AIDS community, it would not take much for people to “put 2 and 2 together”. This person was fully aware that he could be “outing” APHAs just by being friendly! Interview participants were quick to point out, however, that this level of diligence, was not the same in all AASOs.

Different organizations also respond to privacy breaches by staff in different ways. Some organizations vow to terminate an employee for breaching a client’s privacy almost immediately. Other times, especially in the case of an isolated incident and an honest mistake, a staff member may be shown the error of their ways and simply given a warning.

Some interview participants suggested that the level of privacy afforded to clients may have something to do with the type of clientele that walks through the doors. The suggestion is that the more marginalized the clientele population that the AASO serves, the less the expectation of privacy, and the more privacy breaches will be tolerated. For example, one front line worker in an inner-city, impoverished area said that he was aware of “tons” of APHA privacy breaches within the community he serves. A significant proportion of his organization’s clients are Aboriginal. He indicated that the more marginalized people are (e.g. the poor, the disadvantaged, the mentally ill, the street-involved), the more “third parties” they will have in their lives, and therefore the more potential they will have for privacy breaches. These individuals and groups also tend to be the least likely to complain when their privacy interests are compromised.

Issue #15

Working with AASOs: Compromising Your Own Privacy?

Many APHAs try to find some good in their situation by using their experiences to do work for AASOs. This may include being a volunteer, a paid employee or simply participating in an HIV/AIDS event or activity. APHAs sometimes are not aware of all the consequences of doing work for AASOs.

When an AASO asks APHAs to do something for them (e.g. give a speech, take part in a circle), the APHAs may not realize the full implications in terms of their privacy (e.g. they may discover their



information posted on Internet, people think they are open about their HIV status everywhere, they may begin the rumour-mill back in their home communities, etc.). Although APHAs are often asked to sign a waiver before taking part in certain types of activities, the purpose of the waiver tends to be for the protection of the AASO and not to inform the APHAs of exactly what is in store for them.

This is a growing problem, especially relevant in the age of the Internet. For example, an APHA may agree to share his/her story in a newsletter with limited distribution or during a talk at a conference with a small, specific type of audience. However the APHA may not realize that in today's information age, many newsletters, conference programs, speaker lists or event summaries find their way online, and accessible to anyone with a computer. For an APHA active in the HIV/AIDS movement, entering their name in an Internet search engine (such as "Google") can lead to a surprising discovery about how much of their personal information has made it into the public domain.

Issue #16

Becoming an HIV/AIDS "Poster Person"

During the APHA interviews, it was described how easily it was to become a "poster-person" for the HIV/AIDS movement, whether or not that was the APHA's intention. For example, an APHA may become a "star" within the HIV/AIDS movement (i.e. become very well known) without even realizing it, just by the amount of HIV/AIDS work they have done, or how long they have been involved in the movement. When an APHA does become a "star", it becomes a common assumption that they are open about their HIV status everywhere, or that everybody knows their HIV status, and the usual privacy precautions offered other APHAs may be relaxed.

An APHA can also become a victim of his/her altruism in another way: all of a sudden others start expecting more work from them and expect them to always be giving of themselves (e.g. have their name published, appear on posters, share their story at conferences, etc.). The APHA community is still relatively small and the peer pressure to become even more public about your HIV status (after your initial disclosure) can be quite intense. This pressure may be increased if the APHA is from an Aboriginal population which does not have many active representatives within the HIV/AIDS movement.

This type of pressure can then cause other APHAs to be hesitant to become involved in the movement (e.g. risk becoming a poster person, risk the pressured to do things that they do not want to do), attend conferences, or even access AASOs. APHAs finding themselves being pressured into this role may eventually react by withdrawing from the HIV/AIDS movement altogether.



6. HIV/AIDS Conferences or Gatherings

A common theme throughout the APHA interviews was the complaint that when people see APHAs involved in the HIV/AIDS movement in any way, they assume that they are open about their status in other parts of their lives. This is the type of thinking that causes many privacy challenges for those wishing to attend HIV/AIDS conferences.

For APHAs, the benefits of attending HIV/AIDS conferences cannot be understated. The atmosphere of support, openness and community that characterize these gatherings is something that every APHA should have the opportunity to experience at least once. For many attendees, especially those from smaller, more isolated communities (that do not have any AASOs or ASOs), these events are the only places where they can truly feel free to be themselves and be around others who know what they are going through. Unfortunately, the openness of a public gathering creates a whole new category of privacy challenges.

Those who attend HIV/AIDS conferences include physicians, nurses, nurse practitioners, physician assistants, prevention specialists, health planners, social workers, counsellors, various community members, certified health education specialists, pharmacists, administrators, correction officers, substance abuse counsellors, caregivers, service providers, volunteers, students and practically anybody who is affected by HIV/AIDS either personally or professionally. For the APHA who is not yet open about his/her HIV status, there is no telling who he/she will run into at these events.

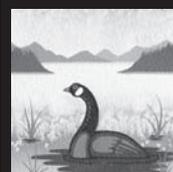
To attend these conferences, it is essential that an APHA give up a certain amount of their own anonymity with regards to their HIV status. However, attending these conferences should not necessarily mean that an APHA has given up all of his/her privacy expectations. Reasonable privacy precautions must still be taken so that attending these events does not equate making a public announcement about your HIV status.

Interview participants overwhelmingly had positive feedback regarding these conferences. If anything, they insisted that more APHAs should be able to attend, family members and life partners should be able to accompany them, and that Aboriginal leadership and public representatives should be invited to see what is happening in their communities. However, they did point out several basic privacy issues that can be addressed in order to create a more secure, private experience:

Issue #6a Registration

For some interview participants, having to give their full name to register for a conference and check in to their hotel rooms was identified as a privacy concern. Especially when APHAs are attending conferences for the first time, having the option to attend with a certain amount of anonymity can be an important psychological incentive to come out and participate.

This is a difficult situation to address since with the travel, accommodations, and other associated costs, it is unrealistic for APHAs to be able to attend anonymously. However, there are ways to make



the experience somewhat more private. For example, having the option of being able to check into the hotel where the conference is being held without being required to give a credit card or a real name (or even staying at a different hotel altogether) is a simple measure that may make some APHAs feel more secure.

Issue #6b

The Rumour Mill

Being spotted at an HIV/AIDS conference for the first time by someone from your home community is a likely way to start the “rumour mill” going. This is one of the biggest fears that recently disclosed APHAs have about attending. This is an unfortunate consequence of attending a public event and there is not very much that organizers can do to prevent this. However, the issue must be acknowledged in some way. Perhaps a brief announcement at the start of the conference may be helpful in reminding participants not to assume that people are “out” about their HIV status everywhere, or even that they are HIV-positive to begin with.

Issue #6c

Cameras

One of the more common complaints involved the use of cameras and video-cameras at conferences. APHAs who are “just coming out” about their HIV status often do not want to have their picture taken at these events, but it has been suggested that it happens all the time. At conferences there often seems to be a snapshot being taken or something being videotaped. Occasionally there are announcements asking everyone who does not want to be in the picture to step to the side. Other times a conference attendee can simply be caught off guard with a flash in the face.

Issue #6d

Sharing Other People’s Stories

During workshops with group participation, sometimes the stories or anecdotes that are told can identify a certain APHA to the participants. This is especially true in the Aboriginal community and Aboriginal HIV/AIDS movement in particular, which is a very small community in many respects. Although the workshop facilitator/presenter is expected to take special precautions to disguise identities, participating audience members sometimes do not. The APHA community is relatively small and word gets around quickly when there are incidents that involve its members. A warning to use caution to respect privacy when giving examples of challenges faced by other APHAs may be a good way to start these workshops.

It has also been suggested that according to Aboriginal traditions, no one has the right to tell another person’s story without their permission (even when identifiers are removed from their story). In a



traditional context, someone could not tell certain stories that belonged to individuals, clans, families or communities without proof of a right to do so. Proof was usually through an oral history of lineage. If it was not your story, then it was not yours to share.

Issue #6e

Sharing Circles / Talking Circles

There was also some concern expressed about the confidentiality of the “sharing circles” or “talking circles” that are common features at conferences and gatherings. For example, at one circle there may be around 6-10 participants (or more) present, and a new participant APHA may have the expectation that whatever is said within the circle will stay inside the circle. Although confidentiality is a major component of a properly functioning circle, some interview participants indicated that this is not typically the case (e.g. through comments like “the only place I came out was in the circle!”). Merely the suspicion that confidentiality will not be respected can lead APHAs to keep their stories to themselves and not participate in this type of healing. This is a significant problem because these circles are an important and culturally relevant step in many APHAs’ holistic healing process.



7. Addressing Breaches of Privacy

Considering the number of times that APHAs have to talk to someone about their confidential health information, the potential for unauthorized disclosure is staggering. As with many of the examples already mentioned, the potential for compromising privacy is always greater in the smaller communities where everyone is a familiar face.

When APHAs feel like their privacy is being compromised, often times they do not say anything about it. Even when they do gather the courage to make a comment or question a practice, their actions are limited by the fear of “not wanting to rock the boat”. This is a very common thing in Aboriginal communities, especially smaller ones with limited resources. Some APHAs reported that even if they knew that their privacy was being unjustly infringed (as opposed to merely suspecting it, or even questioning the possibility of a breach), they still would not say anything about their privacy concerns. They often feel that the quality of services they receive would only get worse if they were to complain or question practices.

When APHAs feel that their privacy has been compromised around the time of their initial HIV test or shortly after they are first diagnosed, it is especially unlikely that they will complain about it. There is so much going on mentally and emotionally when they first hear they are HIV-positive that the idea of their “privacy rights” may not even occur to them for years. It can take a very long time to get their heads straight and accept their status. Only then, when they look back, do they start to realize they may have been treated unfairly.

During the interviews, we explored why APHAs do not use the legal system to address privacy breaches. A summary of this issue is included as an appendix to this document. A common theme among interviewed participants knowledgeable of the legal system was the suggestion that in order to effectively address the issue of APHA privacy protection, then our focus should be on prevention. The legal system is a reactive system: it looks at dealing with privacy breaches after they have already occurred (i.e. fixing the problem after the fact). The way to deal with privacy breaches is through prevention (i.e. fix the problem before the breach happens). After all, once an APHA’s privacy is lost, it is gone forever.

It is in the spirit of prevention that the Aboriginal HIV/AIDS Privacy and Confidentiality Initiative determined that the primary focus for AASOs should be on creating environments that are more sensitive to these privacy and confidentiality issues. The first step in achieving this goal is to ensure that all AASOs have a fully developed privacy policy in place in a language which is both understandable and meaningful for staff, volunteers, clients and all interested parties.



8. Example Privacy and Confidentiality policy

The following is an example privacy policy which addresses the issues raised by interview participants. The sections are based on the confidentiality policies voluntarily submitted by participating ASOs and AASOs, as well as recommendations by interview participants. The most common interview participant recommendation was for the policy to be presented in an easy-to read format.

Our intention is not simply for AASOs to adopt this example privacy policy verbatim (although they may certainly do so if they wish). The purpose here is to have these organizations take a look at their own existing privacy guidelines and see how they compare with this example policy. Do their own guidelines address all of these issues? Do they have all of these basic features? Is there anything that they should add or modify?

What is important here is to begin a dialogue: to get all members of AASOs - including staff, volunteers and Board members - to start thinking and talking about the privacy and confidentiality concerns of their clients and the communities that they serve.

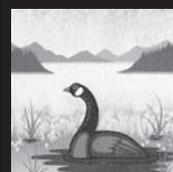
“The Agency’s” Privacy and Confidentiality Policy

A. Policy Statement

Confidentiality reflects traditional Aboriginal teachings about respect for the individual and is also an ethical and legal obligation, based on the rights of individuals and the community to the protection of intimate personal disclosures made in a professional relationship. These confidentiality guidelines apply to everyone associated with the agency who have access to personal, health and agency information as a result of the performance of their duties. The agency recognizes the need to ensure all reasonable privacy and safety to those it serves. Credible service is based on trust, respect, sensitivity and competence. Whenever possible, we ensure complete confidentiality to our employees, volunteers, clients and anyone in the communities we support through our programs.

B. Basic Principles

- APHAs have the right to privacy and confidentiality regarding their HIV status and other related health information.
- All staff, volunteers and Board members have a duty to ensure the privacy and confidentiality of all information concerning the affairs of a client acquired in the course of the professional relationship.
- There are different degrees of HIV disclosure. It is an APHA’s right to control how, where, when and to whom the disclosure of their HIV status is to take place.
- Maintaining the trust and confidence of the community is essential for the existence of *the agency*. A breach of privacy is really a breach of this trust.



C. Limits to Confidentiality

Within the context of their work, staff, volunteers and Board members may be faced with circumstances which call for professional judgment regarding confidentiality when a person is incompetent. Some situations will require that action(s) be taken and confidential information shared without the consent of those involved. Such situations include the following:

- Reporting of HIV and AIDS under public health laws.
- When ordered to disclose information by a court of law (search warrants and subpoenas).
- The need for immediate medical attention.
- Indications that a child is at risk.

D. Definitions

For the purpose of this policy, keeping something confidential means that information will not be released without specific authorization of the individual concerned.

Matters which will be kept confidential include anything that could identify a contact or information seeker of the agency, and everything related to the health and personal files of the agency's contacts, information seekers, employees, placement students and volunteers.

Examples of confidential information includes, but are not limited to, names, medical condition and treatment, finances, living arrangements, employment, sexual orientation, and relations with family members.

E. Procedures

- As a staff member, volunteer or Board member of *the agency*, you will become aware of personal and sensitive information and situations which must remain confidential. This means thinking carefully before passing on personal information that you have, and before asking people to give you personal information. This includes showing respect for others by NOT asking questions such as:
 - Do you have HIV or AIDS?
 - How did you become HIV positive?
 - Are you on the cocktail?
 - Are you gay, straight, two spirited?
 - Do you use [street] drugs?
- Whenever possible, the work of *the agency* shall be carried on in a manner so as to protect the client's privacy and any confidential information.
- All clients' identifiable information will be disclosed only on a "need to know basis".
- In situations where disclosure of confidential information is necessary, or where disclosure is authorized by the client, no more information should be divulged than is required.
- If participation in a committee, research project, gathering, or other activity implies that a



person is HIV-positive, then the person's very participation in the activity should be kept confidential.

- All persons in possession of confidential information should avoid taking part in gossip about such information, even with one's co-workers, spouse or family. Special care should be exercised even if the client's name is not revealed because it is often possible to identify a client by the unique facts of his or her case.
- The agency will protect personal information with appropriate security safeguards. Safeguards include physical (e.g. locking up information), administrative (e.g. client codes), and electronic (e.g. appropriate use of passwords) security measures.
- All new staff, volunteers and Board members should undergo an orientation on privacy and confidentiality.

F. Orientation on Privacy and Confidentiality

All representatives of the agency - including staff, volunteers and Board members - should be made aware of this confidentiality policy and related personnel policies.

When first hired or approved by the agency, staff, volunteers and Board members are required to read the confidentiality policy and discuss it with their supervisors. They are then required to sign a policy undertaking which they have read, understood and by which they agree to abide (please see "Employee Confidentiality Undertaking" below).

G. Breach of Confidentiality

As a staff member or volunteer, it is imperative that you speak with a supervisor if any of the following occur:

- You do not completely understand this policy.
- You are unsure about whether or not something would be a breach of confidentiality.
- You believe that a breach of confidentiality has taken place.
- You find yourself in a situation where your confidentiality has been compromised.

Violation of the organization's confidentiality policy by a staff member, volunteer or Board member may result in dismissal or removal from office. In any case, the supervisor shall set up a meeting with the person in question to discuss the issue and appropriate disciplinary and/or educational action shall be taken to address the situation.

Confidentiality extends not only for the duration of the service contract but also continues indefinitely once the relationship with the agency has ceased.



H. Policy on HIV-Positive Employees

In keeping with the agency's policy on confidentiality, all health related information for staff, volunteers and Board members must be kept confidential. HIV status is only relevant if the employee wishes it to be known. All self-disclosed APHAs must remain self-disclosed. They may disclose their status only if they wish.

Employee Confidentiality Undertaking

I, the undersigned, have read and understood the agency's policy on confidentiality. I understand that the agency's service to the Aboriginal community is based on mutual trust, respect and sensitivity. I have discussed the confidentiality policy with my employer and agree to abide by all aspects of it.

Name

Date

Witness

Date



9. Some closing thoughts

If there is one thing that our privacy interviews have taught us, it is that we cannot accomplish anything by punishment alone. Knowledge and education is the answer.

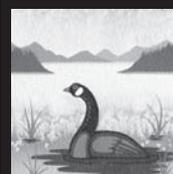
The purpose behind HIV/AIDS privacy protection is not about punishing gossipers but rather about addressing the stigma goes along with being HIV positive. Our goal is to try and create an environment where discussing someone's HIV status becomes a good thing: where talk of HIV can be breakfast table conversation with your children and not rumors heard through the grapevine. We want to create an accepting environment where privacy is respected... and where APHAs are respected.

As suggested during the interviews, "privacy", at least in terms of information relating to health, is not even a typical Aboriginal traditional or cultural value. In a traditional sense, Aboriginal communities needed to know when someone was ill because the whole community was responsible for caring for the sick. It should be pointed out that the ultimate Aboriginal goal is to eliminate all HIV/AIDS stigma so that confidentiality is no longer necessary or desirable.

Until that day comes, having people know that you are HIV-positive can open the door to stigma and discrimination in virtually every part of your personal and professional life. Despite more than two decades of research and public education about HIV/AIDS, ignorance and stereotypes continue to shape much of society's reaction to APHAs. It can be difficult to predict how people will react, or how someone's life may change, if and when their HIV status becomes known by others. In light of the potential consequences and possible life changes that may follow, it should be every APHAs right to control how, where, when and to whom the disclosure of their HIV status is to take place.

There are varying examples out there, for how agencies and service providers seek to respect and protect the privacy and confidentiality of APHAs or service-users in general. The Aboriginal Healing Foundation for instance, has all employees and contractors sign a Code of Conduct. This document explains the reasons why confidentiality is important and the consequences when this is breached. Other agencies may have a zero-tolerance policy on things like gossip, where they inform new employees of their responsibility to maintain a professional conduct on what they become privy too through their work. While there are different legislations out there, these may vary from jurisdiction to jurisdiction. For example, an Indian Reserve is federal jurisdiction whereas a Métis Settlement is Provincial, and an Inuit Hamlet is Territorial. This too can affect what remedies there are when a person chooses to pursue and file a complaint.

If there were to be one golden rule, it may be as simple as always asking an APHA before you disclose any information, rather than after. Even when someone is on a poster outing themselves and disclosing their HIV status, it is best to err on the side of caution instead of assuming it is ok to reveal personal information.



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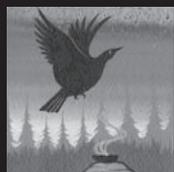
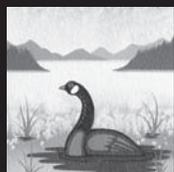
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Appendix - The Legal System

For APHAs, what kind of privacy protection is offered by the Canadian legal system?

When it comes to an APHA's rights under the Canadian legal system, it is important to distinguish between "theory" (what is possible) and "practice" (what actually happens).

In theory, an APHA's privacy interests are protected in all sorts of documents (human rights instruments, federal and provincial privacy legislation, professional codes of conduct, etc). However, on a practical level, APHAs tend to discover that the legal system does not offer them very much privacy protection at all.

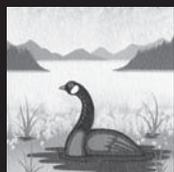
First of all, there are very few Canadian laws that govern private relationships between individuals. For example, if an acquaintance is telling others about your HIV status, then you probably do not have any enforceable privacy rights at all (unless the act is illegal in some other way, e.g. threatening someone). APHAs are often surprised to hear that there is very little they can do about a friend, family member, or acquaintance spreading information about their HIV status.

Although Canada has a variety of laws governing the collection, use and disclosure of personal information, it is important to keep in mind, that the bulk of Canadian privacy legislation tends to only protect an individual's "privacy" in a very limited way. Most of the legislation concerns itself with the disclosure and collection of private information and provides individuals with few actual enforceable entitlements. Furthermore, the process of accessing effective remedies under our privacy laws can also be very complex. Also, APHAs may find that the types of remedies that are ultimately offered (e.g. a letter of apology, getting an organization to change their practices) may seem inadequate and not be worth the time or effort of pursuing a complaint.

Even when laws are passed that do provide greater privacy protections, they do not apply uniformly to all Canadians. The laws that apply to an APHA depends largely on where they reside, where the infraction took place, and who disclosed the private information.

Even in situations where the law and professional codes of conduct clearly do offer the highest degree of privacy protection, such as in the medical community, APHAs continue to report breaches of privacy at their local doctor's office, nursing station or medical clinic.

Overall, the legal landscape is getting more complex when it comes to privacy. We have had some positive changes in the legislation but the fact remains that our privacy laws are very complicated. In some cases, numerous pieces of legislation can apply in one place. Sometimes you need a lawyer experienced in privacy law just to determine what is going on. The sheer complexity makes the system inaccessible. Attempting to improve the system would require people-centred reforms and more effective protections.



Why don't APHAs use the legal system to protect their privacy interests or address privacy breaches?

In certain cases APHAs do in fact have enforceable rights when they experience a breach of privacy, yet they do not take action to enforce their rights. Interview participants identified numerous barriers APHAs face when trying to access the legal system for privacy and confidentiality breaches:

Cultural Barriers

This includes the difference between Aboriginal cultural values and a seemingly “foreign system of justice”; the traditional distrust many Aboriginal communities have towards the Canadian legal system; and community pressure to avoid involving the legal system in a dispute.

Financial Barriers

This involves the lack of financial resources of many APHAs. Factors include legal aid cuts; lack of funding; and lower socio-economic status of Aboriginal people.

Access to Information

This includes not knowing that a privacy breach has been committed; not knowing where to file a complaint; and not knowing your rights.

Language Barriers

Language barriers may hinder access to information and services. The unique language of the law and legal documents is another barrier. There is also a lack of reader-friendly legal information available to APHAs.

Lifestyle Issues

These are the unique challenges faced by marginalized groups such as street-involved individuals, prisoners and people of limited means. People who rely heavily on social services are often not in the best position to file complaints. When they do consider making a complaint, their credibility becomes an issue and they have a genuine fear of not being taken seriously.

Specific/Multiple/Simultaneous Discrimination

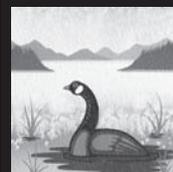
Interview participants discussed the institutional racism at every stage of the legal system. They also talked about the combined discrimination facing people who belong to more than one marginalized group at the same time (e.g. Aboriginal, HIV-positive, alternative lifestyles, women, youth).

Access to Legal Advice

Factors include finding a lawyer knowledgeable in privacy issues; being able to speak to a lawyer; reluctance of lawyers to represent certain individuals or to take on human rights cases; the intimidation of the legal profession; and consultation fees.

Filing a Complaint

(e.g. with the privacy commissioner or with a professional board) – Factors include the complexity of process and procedures; the investment of time and energy; the frequent delays; and a lack of assistance with filing a complaint and filling out documents.



In some situations where an organization breached an APHA's privacy, the APHA may have been able to sue them because there was a recognized duty of confidentiality (e.g. the APHA commonly signs an agreement). In other situations there may have been an administrative process already in place where they could have filed a complaint and held the offending organization accountable. However, the above barriers APHAs face when trying to use the Canadian legal system to enforce their privacy rights are usually enough to discourage even the most adamant of victims.

For the majority of APHAs interviewed, the legal system itself is inaccessible primarily because of cost. Oftentimes legal aid is not available, especially when you are pursuing civil litigation. If you are dealing with a complaint through an administrative tribunal, then you have the problem of finding lawyers who are experienced in this area of law and who are willing to serve you. There are not many lawyers available who do this kind of work.

The challenges APHAs face in accessing the system are related to their resources (both money and access to information). The complaints system and the legal system is very complex. It is not user-friendly. In many communities, ASOs are low in resources and helpful literature to deal with breaches of privacy. The information may be out there, but it is not easy to find, and is not presented in a reader-friendly way. The amount of time required to deal with a breach of privacy through the legal system is another big deterrent.

We do have legislation in place governing the improper use or disclosure of personal information: an APHA could go and complain to the provincial/federal privacy commissioner in the case of a breach of privacy. However, this is easier said than done. For example: (a) the process is not user-friendly; (b) many breaches of privacy are not covered by legislation; (c) the privacy commissioner may have the discretion to decline to deal with a complaint; (d) even if a breach is discovered, the likelihood of accessing effective remedies appears low in terms of an APHA's expectations.

Aside from the inadequate protection offered APHAs by our privacy laws, there are some other, more fundamental problems with using a public system to deal with something as personal as privacy breaches. For example, once an APHA's privacy is gone, there is no way the legal system can restore it. To pursue a claim or file a complaint means involving even more people into the process. This seems to defeat the purpose of trying to protect your privacy through the legal system. Also, what if the offending organization is the only ASO for miles around? What would be the consequences to the APHA for threatening a lawsuit or filing a complaint? Interview participants discussed numerous examples of the social pressures against involving the Canadian legal system what others consider a "community matter".

Perhaps the most significant were the cultural barriers discussed during the interviews. It was suggested that the Canadian privacy laws are designed to protect what "mainstream people" define privacy to be. Aboriginal people and APHAs in particular find that they fall outside this box. The first roadblock APHAs face whenever trying to enforce their rights is the discrimination against Aboriginal people in the legal system. Add to this the discrimination against people living with HIV/AIDS. Then, once APHAs get their foot into the door (i.e. having their complaint taken seriously), they come to realize that the law has been set up according to a White male concept of reality. The rules are different, the values are different, but the prejudice and the phobias are the same.



In general, interview participants felt that the entire Canadian legal system has been set up *not* to protect Aboriginal people, and considering the numerous barriers listed above, it is no wonder why it is rarely used by APHAs to address privacy breaches.

¹Roger Clarke. Introduction to Dataveillance and Information Privacy, and Definitions of Terms. Online: <http://www.anu.edu.au/people/Roger.Clarke/DV/Intro.html>

² Roger Clarke. Introduction to Dataveillance and Information Privacy, and Definitions of Terms. Online: <http://www.anu.edu.au/people/Roger.Clarke/DV/Intro.html>

³Canadian HIV/AIDS Legal Network (2004). Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada. Montréal: Canadian HIV/AIDS Legal Network, p.2.

⁴ In Québec, where the common law does not apply, a person can sue the staff member or volunteer in a civil court based on the privacy protections under the Québec Civil Code and the Québec Charter of Human Rights and Freedoms.

⁵ An example could be a situation where one of the organization's clients reveals during counselling that he/she is putting another one of the same organization's clients at significant risk of serious bodily harm, and the counsellor may be in a position to prevent that harm.



