REDUCING STIGMA AND DISCRIMINATION
through the protection of privacy and confidentiality
ACKNOWLEDGEMENTS

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DEFINING STIGMA

PERCEIVED STIGMA

- Awareness of negative social attitudes, fear of discrimination and feelings of shame.¹

INTERNALIZED STIGMA

- An individual’s acceptance of negative beliefs, views and feelings towards themselves and the stigmatized group to which they belong.¹

ENACTED STIGMA

- Encompasses acts of discrimination, such as exclusion, or physical or emotional abuse (towards an individual’s real or perceived identity or membership to a stigmatized group).¹

LAYERED OR COMPOUNDED STIGMA

- A person holding more than one stigmatized identity (e.g., HIV positive serostatus, sexual orientation, race, ethnicity).¹

INSTITUTIONAL OR STRUCTURAL STIGMA

- Stigmatisation of a group of people by way of policies and procedures.²

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INTRODUCTION

The prevention, diagnosis, treatment and management of sexually transmitted and blood-borne infections (STBBIs), such as HIV, hepatitis, chlamydia, gonorrhea, syphilis and human papillomavirus, are important public health issues in Canada. However, stigma and discrimination within health and social service settings often complicate public health efforts by acting as barriers to clients who try to access and use STBBI-related services.

This resource explains the important role of privacy and confidentiality in reducing stigma and discrimination related to STBBIs within health and social services. It is designed in a question-answer format for use by health and social service providers including physicians, social workers, health educators, nurses and volunteers.

Stigma is a dynamic process of devaluation that significantly discredits an individual in the eyes of others. It manifests in various forms, including internalized, perceived, enacted, institutional, and compounded stigma. If stigma is acted upon, the result is discrimination, which means treating a person differently because of a personal or perceived characteristic.

In Canada, human rights laws prohibit discrimination based on particular grounds, including age, race, ethnicity, colour, religion, sex, marital status, disability, sexual orientation and place of origin. For example, health care professionals cannot refuse to examine or treat a client because of their HIV-positive status as HIV is considered a disability under provincial and federal human rights law.

THE INFORMATION CONTAINED IN THIS RESOURCE WILL ASSIST SERVICE PROVIDERS IN:

- understanding their obligations related to privacy and confidentiality;
- understanding the issues their clients face that contribute to stigma and discrimination (e.g., the criminalization of HIV non-disclosure);
- offering respectful and appropriate care; and
- dealing with difficult dilemmas such as balancing confidentiality with protecting others or public health.

Note: The guidance presented here should not be used as a substitute for legal advice or advice from regulatory bodies about professional obligations and practice standards.
SECTION 1
PROTECTING CLIENTS FROM STIGMA AND DISCRIMINATION THROUGH THE RIGHT TO PRIVACY AND THE DUTY OF CONFIDENTIALITY

Privacy is a fundamental right recognized in international human rights law and Canadian law. It is the right to control or consent to how your personal information is handled by others, including by health and social service providers. By imposing a legal obligation not to reveal personal information without consent, the duty of confidentiality is one way the law protects individuals’ privacy.

WHAT ARE SERVICE PROVIDERS’ OBLIGATIONS WITH RESPECT TO CONFIDENTIALITY?

Talking to clients about their sexual or substance use practices is a common aspect of STBBI-related services. As a service provider, you need to create a safe space for clients to share intimate details and personal experiences without fear of losing control over their personal information or being subject to stigma and discrimination as a result of revealing personal information.

What may appear to you as a minor breach can have severe ramifications for a client if the duty of confidentiality is not upheld. Some examples include:

- Disclosing information about a client’s substance use to others can lead to prosecution, loss of custody of children, or loss of employment.
- Inappropriate disclosure may impact how a client is perceived and treated by other members of the care team.
- Revealing a client’s HIV positive status to a third party may lead to criminal prosecution if the client has not disclosed that status to their sexual partners.
- In communities where homosexuality is highly stigmatized, disclosing a client’s sexual orientation can lead to loss of employment, housing or personal safety.
A service provider’s duty of confidentiality is not limited to a client’s positive STBBI status or any other health condition; it extends to other personal information received in the course of counselling, care and treatment. All discussions with a client about sexual activity, sexual orientation, gender identity or challenges around disclosure to partners are to be kept confidential.

Confidentiality is a legal obligation of all health professionals and frontline service providers involved in counselling, care and treatment.

Depending on the type of service and the nature of the relationship with the client, different precautions are needed to protect confidentiality. Therefore, agencies should consider what ‘protecting privacy’ means, beyond formal systems to maintain files. For example, confidentiality may require that you not communicate, even casually, with the client if you meet outside the office. Revealing that a client knows you may unintentionally reveal that the client has a certain condition, or has accessed a certain program (e.g., HIV support group). This can expose the client to stigma within the community.

PRIVACY AND CONFIDENTIALITY: WHAT IS THE LAW?

The legal framework that protects the privacy of personal information is a patchwork of rules that vary across the country. Determining what laws apply to a particular situation can be challenging.

- Applicable legislation depends on factors such as whether service providers engage in a commercial activity (e.g., physician in private practice) and whether they are members of the private or public sector.
- Legislation varies depending on the type of service provider and the information involved. For example, several provinces have specific legislation imposing obligations on specific professionals, such as nurses and physicians, to protect health information.
- Registered professionals are governed by codes of ethics, rules and standards. As a result, different legislation and rules may apply to different staff members within the same organization. You and your organization should become familiar with legislation applicable to your circumstances.

An overview of privacy legislation in Canada and links to additional resources are available on the Office of the Privacy Commissioner of Canada’s website at https://www.priv.gc.ca/en/ (see Privacy legislation in Canada fact sheet, updated 2014 and The application of PIPEDA to municipalities, universities, schools, and hospitals, updated 2015).

Note that for organizations where no specific privacy legislation applies (such as some not-for-profit organizations in Ontario), staff can follow the general principles found in the federal Personal information protection and electronic documents act (PIPEDA).
WHAT SHOULD SERVICE PROVIDERS TELL CLIENTS ABOUT THEIR DUTY OF CONFIDENTIALITY?

Clients have a right to know how you will use their personal information and with whom it will be shared. There are circumstances where the law authorizes or requires you to disclose confidential information (see below for information on specific circumstances). Clients should be told about such limitations so that they can maintain control of how their personal information will be handled by others.

Clients should be told about practices they might not know about; for instance, that provider-client records can be seized under a search warrant for a criminal investigation, or that the provider is obligated to report a child “in need of protection” under provincial or territorial legislation.

Giving this information to clients may seem counterproductive. You may worry that by talking about the limits of confidentiality, you will discourage STBBI testing or make it impossible to build trusting relationships. But, by being fully transparent about your obligations, you show respect for your clients’ right to privacy and autonomy and set the groundwork for a trusting relationship.

Given the sensitivity of health information and the serious implications of disclosure to a third party, you should talk about the duty of confidentiality and its limits with your clients, rather than solely relying on consent forms and printed copies of policies. (See information below on HIV criminalization and public health interventions.)

Tell your clients about public health reporting requirements that may apply in the STBBI context. For example, advise your clients about your requirement to report known or suspected cases of reportable communicable diseases to public health authorities, and that those authorities will likely require that the client’s sexual partners be notified. This is especially important when discussing STBBI testing with clients. Check your provincial/territorial public health website to find out more about reporting requirements.
WHAT CAN SERVICE PROVIDERS ASK THEIR CLIENTS?

Respecting clients’ privacy goes beyond keeping information confidential. It also means refraining from asking unnecessary, intrusive questions. You should collect information solely on a need to know basis; only ask questions that are relevant to your client’s care.

What you may think is a pertinent question might be rooted in biases and assumptions, or might be perceived as such by a client if you do not explain the rationale for the question and how the information will be kept confidential. Inappropriate questions can compromise the client-service provider relationship, perpetuate stigma (whether internalized, perceived or enacted) and encourage non-disclosure. For example, a sex worker might be reluctant to seek counselling from a physician because of previous experience with inappropriate questions and assumptions voiced by other service providers. Further, asking trans and gender diverse clients questions about their genitalia or surgical status out of curiosity will quickly create a discriminatory environment. Personal information belongs to the client and they have the right to decide whether or not to disclose information, including their STBBI positive status.

Note: Providers should regularly apply universal precautions/routine practices to prevent exposure to potential sources of infectious diseases, regardless of a client’s known or suspected infection status. So, a client’s disclosure of STBBIs is not necessary for you to protect yourself.

WHEN INTERACTING WITH YOUR CLIENTS, BE AWARE OF:

- your own attitudes and values related to STBBIs, sexuality and substance use;
- stigma and violence experienced by clients from marginalized groups such as newcomers, the LGBTQ community, sex workers and people who use substances;
- gender biases and inequalities;
- power dynamics at play between you and your client that may make them feel vulnerable;
- how inappropriate language, questions and assumptions can hurt; and
- how difficult it can be for clients to speak about their sexuality and/or substance use.

WHEN DISCUSSING STBBIS, SEXUALITY AND SUBSTANCE USE, ENSURE THAT YOU:

- only ask questions that are relevant to your client’s care;
- take the time to explain why you are asking a particular question and check whether your client is comfortable with the discussion;
- inform clients they are not obligated to answer any questions with which they are not comfortable;
- use simple and non-judgmental language;
- use open-ended questions to allow clients to tell their own stories; and
- remind clients that the information they provide is confidential and tell them about any limitations to confidentiality.
CAN SERVICE PROVIDERS SHARE CONFIDENTIAL INFORMATION WITH OTHER MEMBERS OF THE CARE TEAM WITHOUT ASKING THEIR CLIENTS FOR CONSENT?

In most cases, a client’s health information can only be disclosed with their consent; but their consent does not always need to be expressed (i.e., stated verbally or in writing). Health care professionals are entitled to assume that their clients have consented to sharing personal health information with other health care professionals involved in their care, including those from different organizations. This practice is called sharing information within the “circle of care.”

In some provinces/territories, this is true unless a client tells the service provider they do not want their information shared. In Ontario, for example, the term “lock box” is used in situations where a client has expressly instructed providers not to share information with others, even if they are involved in their care.

Clients can have good reasons to deny the sharing of their information with other service providers that might not always be evident, including fear of stigma and discrimination. Respecting privacy means that you respect a client’s right to decide when and how their personal information will be shared, used or disclosed.

ONLY NECESSARY INFORMATION SHOULD BE SHARED WITHIN THE “CIRCLE OF CARE”, AND ANY STEPS TO PROTECT A CLIENT’S PRIVACY WHEN DISCLOSING CONFIDENTIAL INFORMATION SHOULD BE TAKEN.

Though it may not be required legally, some health care professionals may want to obtain a client’s express consent in non-emergency circumstances before sharing confidential information with another health professional involved in client care.

For other service providers, it is good practice to ask clients for express consent before disclosing personal information to other staff within the organization, especially sensitive health information. Express consent can protect both the client and the organization.

You can obtain express consent by having clients sign a form giving consent to collecting, using and disclosing information for specific purposes to other providers in the team. Providers working in community organizations, who are not health care professionals, should always get express consent before sharing information with other providers outside their agency.
As a result of stigma and irrational fears (including among some health professionals), people living with HIV and people from other marginalized groups are often perceived as inherently dangerous and needing surveillance. So, reflect on your practices, including the disclosure of a client’s status to other team members. Question whether that disclosure is necessary for the purpose of care, or whether it is an expression of institutionalized stigma or an unjustified fear of transmission.

For more information on privacy in health care settings, see Know your rights, Canadian HIV/AIDS Legal Network, 2014.

**STEPS ORGANIZATIONS CAN TAKE TO BUILD A SAFER AND MORE WELCOMING ENVIRONMENT:**

- adopt policies on privacy, confidentiality and recordkeeping that are clear and easily available to clients;
- question practices and discourses that may be based on prejudice or assumptions about particular groups;
- provide proper training for service providers and support staff;
- appoint an individual or a group to be in charge of privacy-related matters;
- give clients clear information about how the organization deals with a breach of confidentiality, harassment and discrimination, including procedures for client complaints; and
- have staff members sign a confidentiality agreement for the provision of STBBI-related services.
Respecting client confidentiality is central to providing STBBI-related services. But, the duty of confidentiality is not absolute and should be balanced with the protection of others and public health. Balancing public health, client confidentiality and the provision of safe and welcoming STBBI-related services can raise difficult legal and ethical dilemmas.

For example, the current legal environment in Canada reinforces stigma and discrimination against people living with HIV (and potentially other STBBIs) by obliging them to disclose a positive status to their sexual partners.

**SEX, DISCLOSURE, STBBIS AND THE CRIMINAL LAW**

Under criminal law, people living with HIV have a legal duty to disclose their HIV-positive status to a sexual partner when they engage in sex that poses a “realistic possibility of HIV transmission” (as interpreted by the courts). People can be charged with aggravated sexual assault for not disclosing their status even where no transmission occurred and despite having no intention of harming their partners.

The law may be applied differently depending on available medical evidence in a particular case. However, based on the current law, and more particularly on the 2012 Supreme Court of Canada decision in R. v. Mabior, assume that people living with HIV have an obligation to disclose before:

- vaginal or anal sex without a condom (whatever their viral load); and
- vaginal or anal sex with a condom unless they have a low viral load (< 1500 copies/ml).

The law is not yet settled when it comes to other STBBIs. In 1998, in R. v. Cuerrier, the Supreme Court decided that the criminal law could be used to address the risk of HIV infection and other STBBIs. However, the legal test to be applied in cases of other STBBIs is yet to be determined. It is also unclear what other STBBIs might be considered by the courts as serious enough to trigger a legal duty to disclose under criminal law. At present, only a handful of cases have involved STBBIs (mostly genital herpes) other than HIV.

For more information on disclosure of STBBIs and the criminal law, please see Criminal law & HIV non-disclosure in Canada, Canadian HIV/AIDS Legal Network, 2014.
How Does the Criminalization of HIV Non-Disclosure Impact Service Providers’ Work?

By imposing a legal duty to disclose, Canadian criminal law limits the privacy rights of people living with HIV. Because HIV is singled out and because the law allows for prosecutions even where the risks of transmission are extremely low (e.g., condom was used, HIV positive partner had an undetectable viral load), the current criminalization reinforces stigma and discrimination against people living with HIV.

It also risks undermining the relationship of trust between you and your clients, given that medical records can be used in criminal investigations. Further, it contributes to internalized or perceived stigma, and supports a client’s unwillingness to discuss their sexual health and/or disclosure issues or to seek testing. Keep these considerations in mind when working with people living with HIV or seeking HIV testing.

More than 175 people have been charged for not disclosing their HIV status in Canada, so your clients need to know the law so they can make informed decisions. Community-based organizations are often the best or only sources of information and support for people living with HIV. Before discussing the criminalization of HIV non-disclosure, you should first determine if your client has mental or emotional health issues or language barriers that may prevent them from fully understanding the law. Also keep in mind the impact that such a discussion can have on your clients. For example, someone who has just been diagnosed with HIV may not be ready to receive more difficult legal information; so, consider leaving that discussion for a follow-up appointment.

Maintaining supportive relationships, fostering safe spaces and recognizing that real-life experiences are more complex than the criminal law’s interpretations are fundamental aspects of a provider’s work with clients. Racism, gender norms, economic conditions, and cultural and language barriers can affect a person’s capacity to disclose their status, take precautions to reduce risk of transmission, and access support. This is particularly real for anyone living in tight-knit communities where sexuality, substance use and HIV remain taboo. Also, fear of criminal prosecution can make it difficult for clients to be open about an HIV positive status. Respecting where each client is as an individual can help alleviate the stigma they experience.

Service providers cannot provide legal advice, but can provide general information and counselling. Give clients appropriate referrals and materials on criminal law and HIV from reliable sources. Work with them to promote their overall health and well-being, including minimizing the adverse or negative effects of disclosure if they choose to disclose their status. Finally, because your records can be seized for a criminal investigation, your clients may want to get legal advice before further discussions with you.
OBLIGATIONS AND OTHER KEY POINTS:

- A service provider’s role is not to enforce the criminal law, but to provide care and counselling to clients;
- There is no obligation under the criminal law to report a crime to the police or provide the police with information about a client unless such a requirement is set out in a search warrant or it involves a child in need for protection;
- There is no obligation to inform clients about the option open to them to press charges against a sexual partner who may have exposed them to a risk of HIV (or other STBBIs);
- When you decide to take action because you are concerned someone may be at risk for harm, do not go to the police unless it is absolutely necessary because of an exceptional situation. If you or your organization are, or are seen to be, giving information to the police, your work could be compromised;
- If you have a client who has been charged or believes they may be under investigation, direct the client (or their defence lawyer) to Responding to the criminalization of HIV transmission or exposure: Resources for lawyers and advocates, Canadian HIV/AIDS Legal Network, 2010; and
- Tell your clients that defence lawyers can contact the Canadian HIV/AIDS Legal Network, the HIV & AIDS Legal Clinic Ontario (HALCO) (in Ontario) and the Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA) (in Quebec) to discuss the details of their cases. These three organizations routinely work with defence lawyers in cases related to HIV non-disclosure.

HIV CRIMINALIZATION AND RECORDKEEPING

Client’s medical records are often used in criminal investigations for alleged HIV non-disclosure. Given concerns that their notes will be used to incriminate clients, some community organizations have opted to keep all note-taking to a minimum, while continuing to respect the note-taking standards of practice for regulated professions.

When responding to search warrants or subpoenas, consult your organization's policy (if one exists) and the designated responsible person before taking any action. You are under no obligation to turn over any more information or materials than covered by the warrant; and protecting client confidentiality means turning over as little as required. Also, tell your clients about the event and get legal advice quickly after receiving a warrant or subpoena.

For more information on HIV criminalization issues such as counselling, recordkeeping and the duty of confidentiality, please HIV disclosure and the law: A resource kit for service providers, Canadian HIV/AIDS Legal Network, 2012.

Nurses can refer to Legal and clinical implications of HIV non/disclosure: A practical guide for HIV nurses in Canada, Canadian Association of Nurses in AIDS Care (CANAC) and CATIE, 2013.
DO SERVICE PROVIDERS HAVE A DUTY TO WARN OTHERS AT RISK OF HARM?

To date, we are not aware of any reported court decisions establishing a “duty to warn” in the specific context of exposure to STBBIs. In particular, we are not aware of any civil suit against an AIDS service organization or other community service provider for failing to warn a partner at risk of HIV transmission.

However, we know that a few civil lawsuits have been launched against some public health units and police services, alleging negligence for not warning specific individuals potentially at risk of HIV infection from someone else. But, these cases are ongoing and as yet, no judge has ruled that a duty to warn exists with respect to HIV risk. The risk of being successfully sued depends on various factors, including the:

- service provider’s relationship with the person thought to be at risk of harm (whether that person is their client or not);
- nature of the danger, its foreseeability and imminence; and
- mandate of the service provider or organization.

For example, public health departments are more likely to face liability than a community organization, because their specific legal mandate is to protect public health.

Although there is no outright obligation to warn, there may be exceptional circumstances where you feel compelled to intervene. Based on a guiding principle established by the Supreme Court of Canada in 1999, service providers with a duty of confidentiality hold discretion (not an obligation) to disclose confidential information about a client in order to prevent harm to another person where:

- there is a clear risk of harm to an identifiable person or group of persons;
- there is a risk of serious bodily harm or death (i.e., the intended victim is in danger of being killed or of suffering serious bodily harm); and
- the danger is imminent (i.e., a sense of urgency).

However, it is still unclear how such principles would apply to a risk of STBBI transmission.

Regulated professionals usually have laws, regulations or policies specifying when and how client confidentiality may be breached, including a breach to protect a specific third party or the public. You and your organization should be aware of these relevant laws, regulations and policies that may be applicable to their staff members.

In any circumstance, a decision to take action must be carefully thought through, and you should limit, as much as possible, any breach of your client’s confidentiality. Keep in mind that stigma, especially related to HIV and some marginalized groups, can influence your perception of risk and of the need to intervene. If you disclose confidential client information as a first step, you (and your organization) may face a lawsuit from your client. You could also risk exposing your clients to serious harm. Moreover, your organization would run the risk of losing credibility in the community because of breaching client trust.

All service providers should record the reasons for their decision and inform clients of any action to be taken if the chosen action breaches confidentiality. You must give reasonable notice to your client before taking action, unless the circumstances prevent you from doing so (e.g., because it might put the person thought to be at risk at even greater risk of harm).

For more information, please see Disclosing to prevent harm — a decision-making tree in HIV disclosure and the law: A resource kit for service providers, Canadian HIV/AIDS Legal Network, 2012.
WHAT PUBLIC HEALTH INTERVENTIONS ARE AVAILABLE TO PROTECT SEXUAL PARTNERS AND THE PUBLIC FROM STBBI TRANSMISSION?

Physicians or registered nurses may be authorized or required to disclose client information to public health authorities, such as the Medical Officer of Health, to protect public health. Other service providers may choose to contact public health authorities for assistance in circumstances where they feel compelled to take steps to protect others from harm.

The powers and procedures of public health authorities in relation to HIV and other STBBIs vary among the provinces and territories, and include coercive interventions, such as involuntary disclosure to a third party, or the issuance of a written order instructing a designated person to take (or refrain from taking) any action that is specified in the order. For instance, an order may tell an individual to stop engaging in condom-less sex.

Whenever you are considering alerting public health, or whenever public health authorities consider coercive interventions, finding a balance between the rights of the individual and the need to protect the community is crucial. Any voluntary measures already taken have to be considered, and it is important to assess the risks of transmission based on the most recent and credible medical evidence. This is important as coercive interventions can reinforce stigma and discrimination. Generally speaking, the “least intrusive, most effective” graduated approach to interventions should always be followed. Partner notification, whether voluntary or involuntary, should respect client’s anonymity.

CONSIDER THE FOLLOWING FACTORS BEFORE DISCLOSING A PERSON’S HIV STATUS TO A THIRD PARTY:

- the person’s HIV status is confirmed as positive;
- there are reasonable grounds to conclude that the person is engaging in behaviour that may put others in harm;
- the person has been offered support, education and counselling and is unwilling or unable to alter their behaviour;
- the person is unwilling or unable to inform a third party who is at risk of HIV transmission about their HIV positive status;
- the person has refused the offer of a physician and/or medical officer of health to inform the third party on their behalf;
- there is no mitigating reason to postpone or reconsider informing the third party of the person’s HIV positive status;
- there are reasonable grounds to believe an identifiable third party or third parties is/are at continued risk of HIV transmission because of the infected person’s behaviour;
- the third party has no other reasonable way of knowing their risk, or is unable to assess their risk of HIV infection; and
- before disclosing to a third party, the medical officer of health should inform, or make reasonable attempts to inform, the infected person of their intention to disclose information to a third party without the person’s consent.

- Excerpt from the Guidelines for medical health officers: Approach to people with HIV/AIDS who may pose a risk of harm to others, BC Centre for Disease Control, 2010.
### FOR MORE INFORMATION

**STIGMA IN HEALTH AND SOCIAL SERVICE SETTINGS**

**PRIVACY LEGISLATION IN CANADA**

**HIV DISCLOSURE AND THE LAW**

**HIV DISCLOSURE AND THE CRIMINAL LAW**
- Watch a series of videos (in English and French) about HIV and the criminal law at [www.youtube.com/aidslaw](http://www.youtube.com/aidslaw).

**HIV CRIMINALIZATION AND ITS IMPLICATIONS ON NURSING PRACTICES**
- Legal and clinical implications of HIV non/disclosure: A practical guide for HIV nurses in Canada. Canadian Association of Nurses in AIDS Care (CANAC) and CATIE, 2013.

**HIV DISCLOSURE IN HEALTH-CARE SETTINGS**

**TESTING AND HUMAN RIGHTS**

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