

Reducing STBBI-related stigma through the protection of privacy and confidentiality

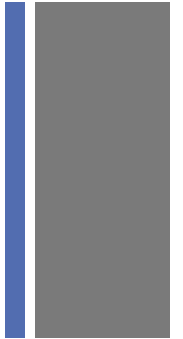
Canadian Public Health Association (CPHA) in
partnership with the Canadian HIV/AIDS Legal
Network, 2016



Goals

- To discuss the role of privacy and confidentiality in reducing stigma and discrimination within health and social services
- To learn more about your obligations as a service provider with regard to privacy and confidentiality
- To explore what you can do to create safer and more inclusive spaces for people who use services related to sexually transmitted and blood-borne infections (STBBIs)
- To develop a better understanding of some of the issues faced by people who access STBBI-related services, inside and outside the service environment
- To learn how to address ethical dilemmas

This information cannot be used as a substitute for legal advice nor can it be used as a substitute for advice from regulatory bodies about professional obligations and practice standards.



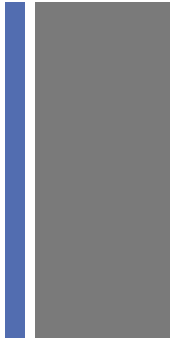
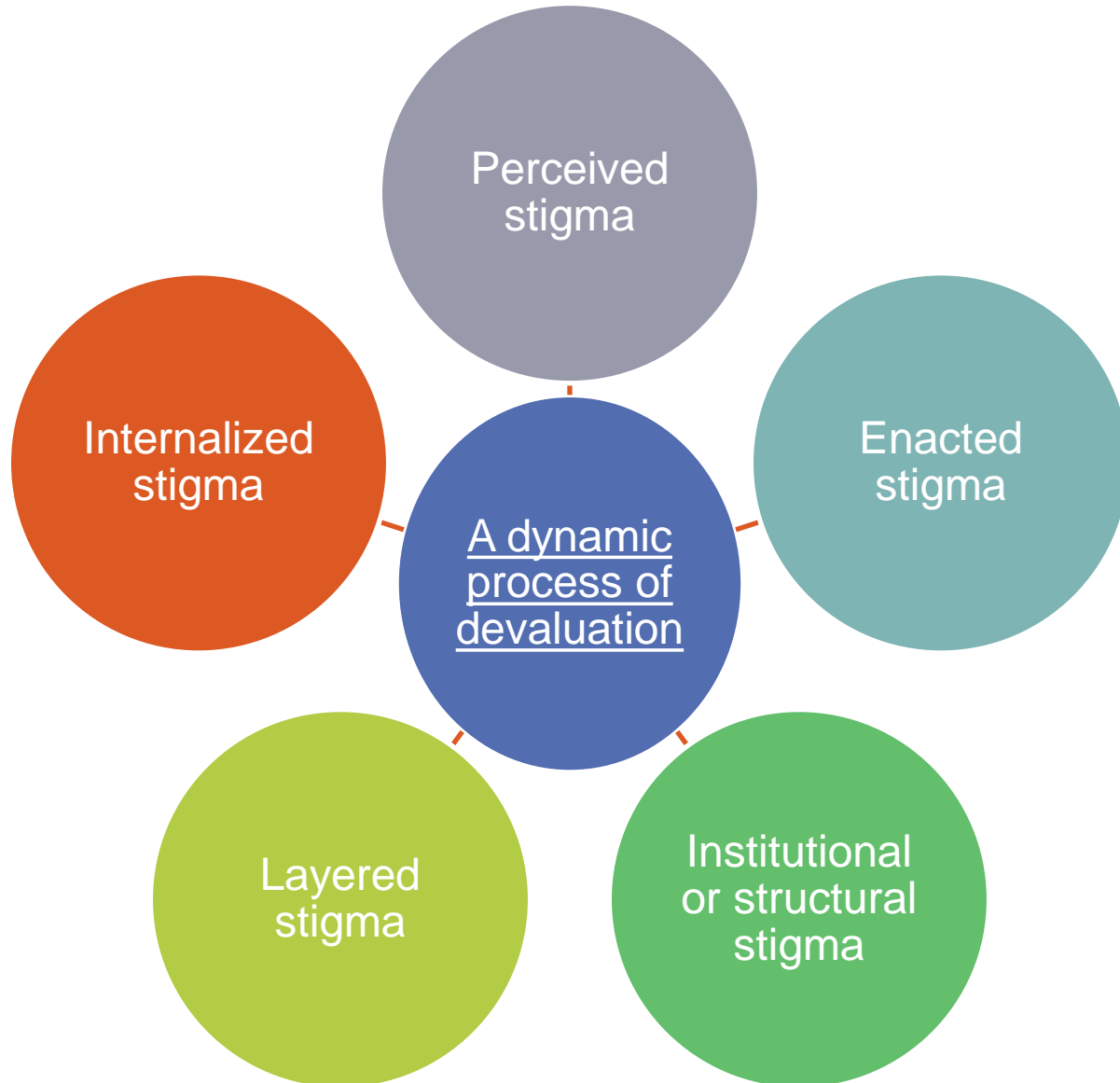
+ Stigma

Brainstorm discussion

- What is it?
- Where do we see it?
- What is its impact?



+ Multiple forms of stigma



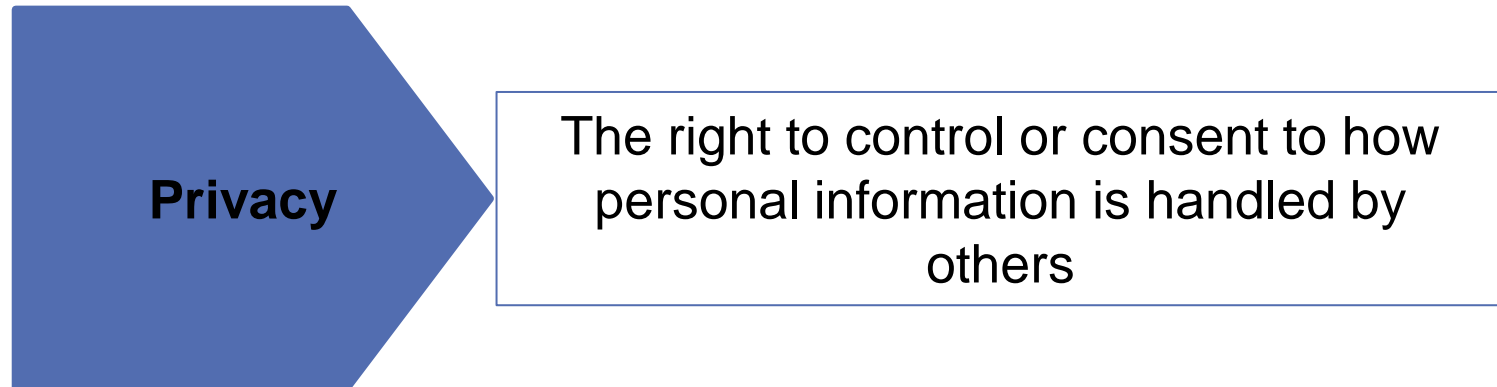
+ Discrimination

- **Discrimination** = Treating a person differently because of a personal or perceived characteristic.
- Discrimination on certain grounds including age, race, ethnicity, colour, religion, sex, marital status, disability, sexual orientation and place of origin is prohibited by Canadian human rights law.
- By guaranteeing **privacy and confidentiality**, health care and social service providers protect against stigma and discrimination.



+ Privacy and confidentiality

- **Privacy** is a fundamental right recognized in international human rights law and Canadian law.
- By imposing a **legal obligation not to reveal personal information without consent**, the duty of confidentiality is one way the law protects individuals' privacy.

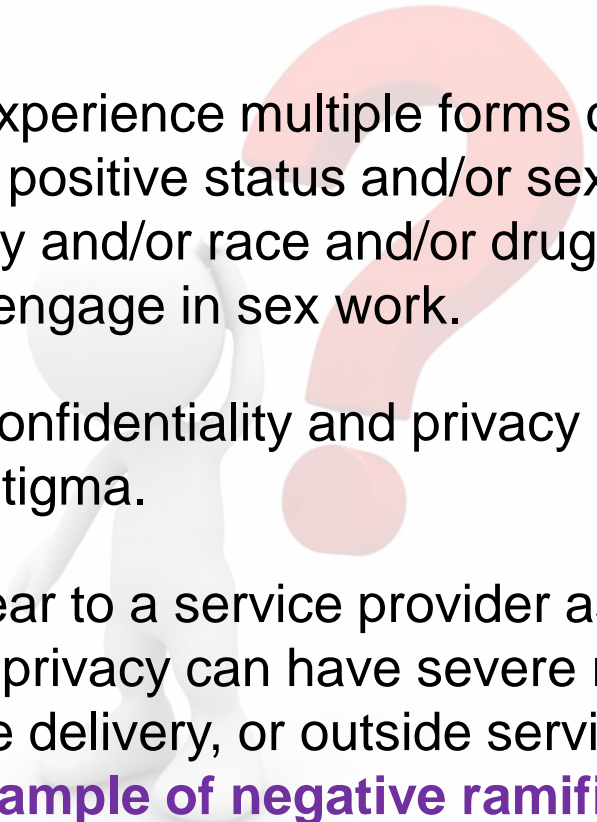




I. Protecting clients from stigma through privacy and confidentiality



- Service users may experience multiple forms of stigma because of their HIV positive status and/or sexual orientation and/or gender identity and/or race and/or drug use and/or because they might engage in sex work.
- Respecting client's confidentiality and privacy is important to protect clients from stigma.
- Even what may appear to a service provider as a minor violation of a client's privacy can have severe ramifications in the context of service delivery, or outside service delivery. **Can you think of one example of negative ramification?**



+ Privacy law in Canada

A patchwork of rules that can vary across the country

Federal and provincial privacy law (public sector)

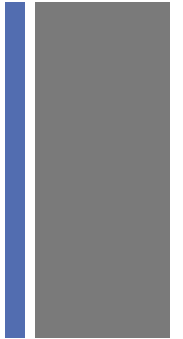
Provincial legislation applicable to health information

Personal Information Protection and Electronic Documents (PIPEDA)
(federal; private sector; some provinces have substantially similar legislation)

Professional codes of ethics, rules and standards

+ Confidential information

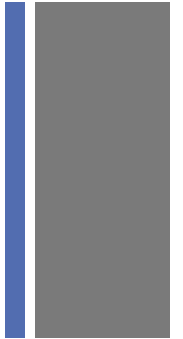
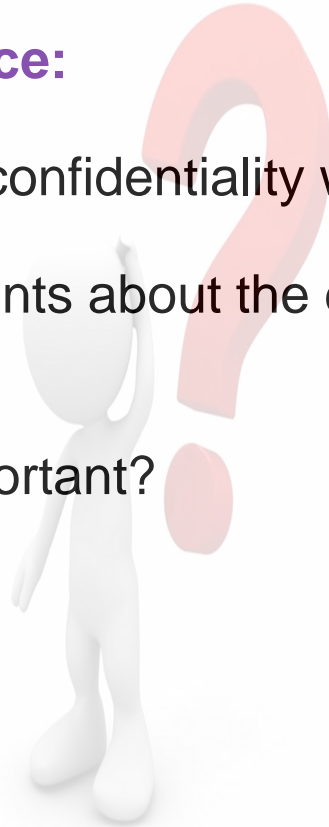
- Service providers' duty of confidentiality is not limited to clients' STBBI-positive status or other health conditions but extends to other personal information a service provider may receive in the context of counselling, care and treatment.
- Any discussions a service provider may have with a client about their sexual activity, their sexual orientation, their gender identity or their challenges around disclosure to partners are to be kept confidential.



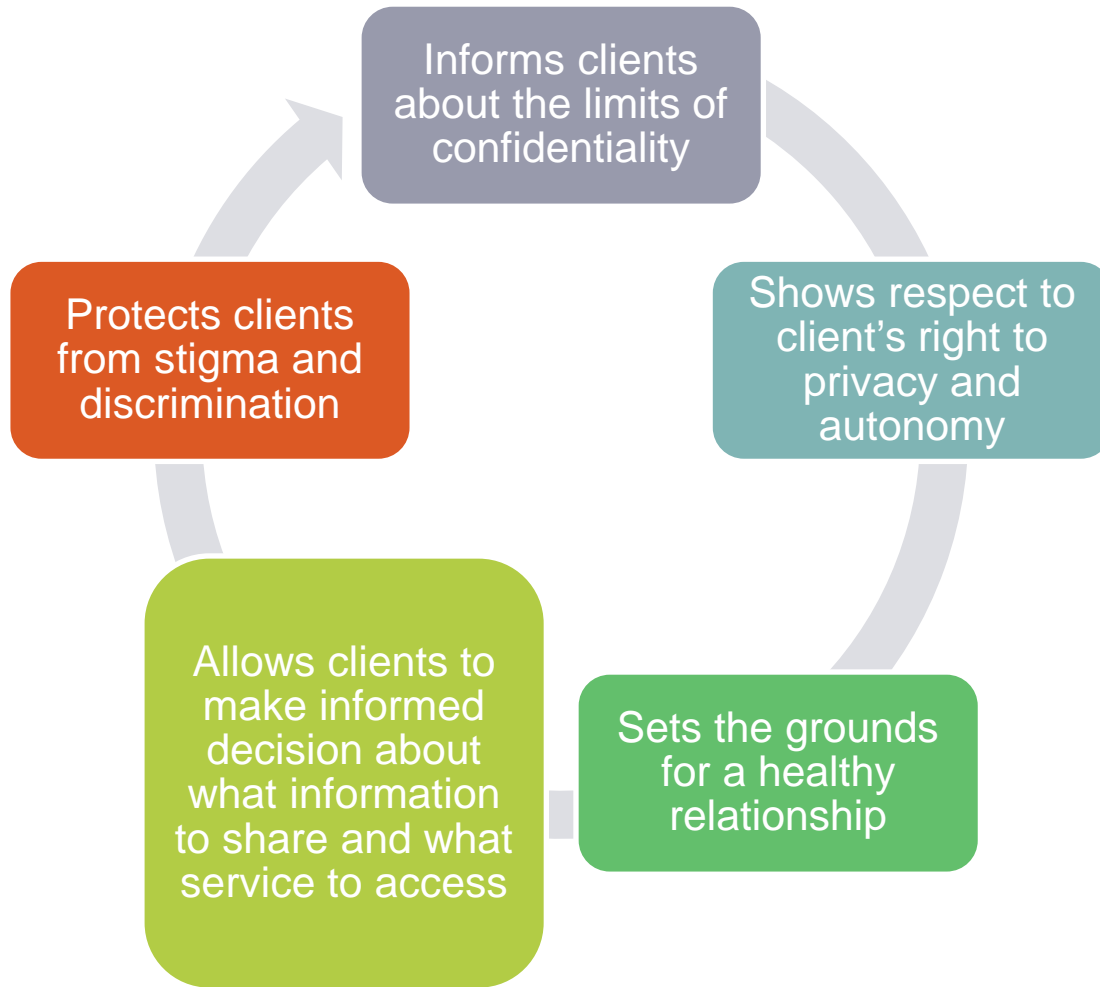
+ The duty of confidentiality

Reflecting on your own practice:

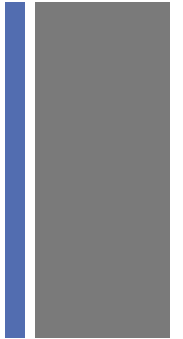
- Do you talk about the duty of confidentiality with your clients?
- If so, what do you tell your clients about the duty of confidentiality?
- And why do you think it is important?



+ The duty of confidentiality



+ Respecting clients' privacy



- Respecting clients' privacy also means **refraining form asking unnecessary intrusive question**. Service providers should only collect information on a *need to know basis*.
- If a service provider asks a question or gives advice that is unnecessary intrusive and/or rooted in biases and assumptions, or that is perceived as such by a client, this will negatively impact the client-service provider relationship and the health and well being of the client.

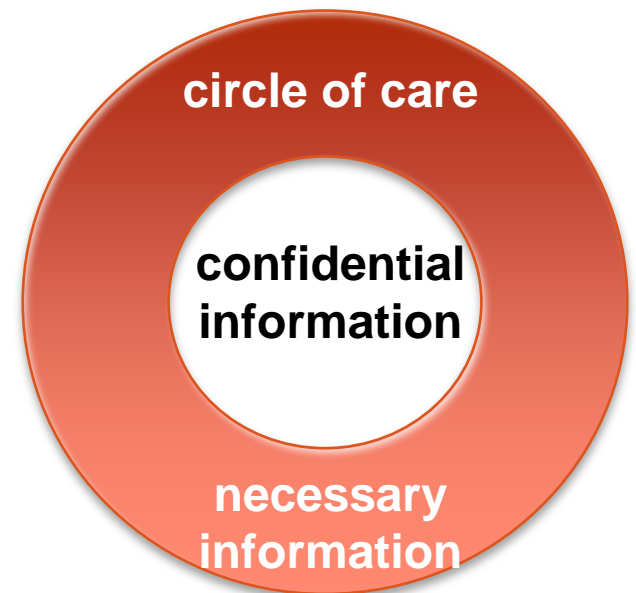
+ Interacting with clients

- Service providers should
 - **be aware of their own attitudes, values and possible bias**
 - **be aware of factors that may impact a client's capacity to disclose personal information** and/or impact the way they might receive questions (e.g. stigma and discrimination experienced by marginalized groups, including in health care settings).
 - **know why they are asking a question**, and ensure it is relevant to the care. Questions should not be asked out of curiosity.
 - as appropriate, **take the time to explain why they are asking a particular question** and check whether clients are comfortable continuing the discussion. Mention that they are not obligated to answer any questions they do not feel comfortable discussing.
 - use simple, non-judgmental and understandable language to **avoid misunderstandings**.
 - tell clients that the information they provide is confidential and **discuss any limitations to confidentiality**.

+ Sharing confidential information

- In most cases, clients' health information can only be disclosed with their consent — but their consent does not always need to be express (i.e., stated verbally or in writing).
- Health care professionals are often entitled to assume that their clients have consented to the sharing of their personal health information **with other health care professionals** involved in their care, including health professionals working across different organizations.

Only **necessary information** should be shared within the circle of care, and service providers should always take steps to protect their clients' privacy when disclosing confidential information. This is extremely important to ensure a non-stigmatizing and non-discriminatory environment.



+ The circle of care: exceptions

- In some provinces/territories, this practice applies unless a client has told their service provider they do not want their information to be shared with another health care professional.
- Clients may have good reasons to ask for their information not to be shared with other health professionals, including fear of stigma and discrimination, that might not always be evident.
- Respecting privacy requires services providers to respect their clients' right to decide for themselves when and how their personal information will be shared, used or disclosed.

+ Other circumstances

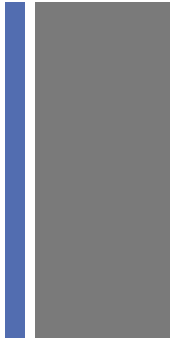
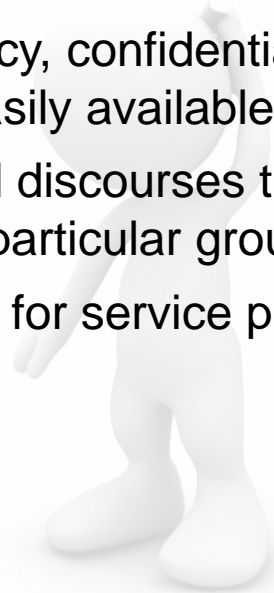
- In other circumstances that do not involve health care professionals, it is good practice to ask clients for their **express consent** before disclosing personal information, especially health information.
- Asking for express consent can help protect both the client and the organization.



+ Moving forward

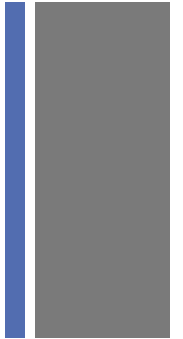
■ What are some steps organizations can take to facilitate a non-stigmatizing and non-discriminatory environment through respecting and promoting privacy and confidentiality?

- ❑ Adopt policies on privacy, confidentiality and record keeping that are understandable and easily available to clients;
- ❑ Question practices and discourses that may be based on prejudice or assumptions about particular group;
- ❑ Provide proper training for service providers and support staff;
- ❑ Other?

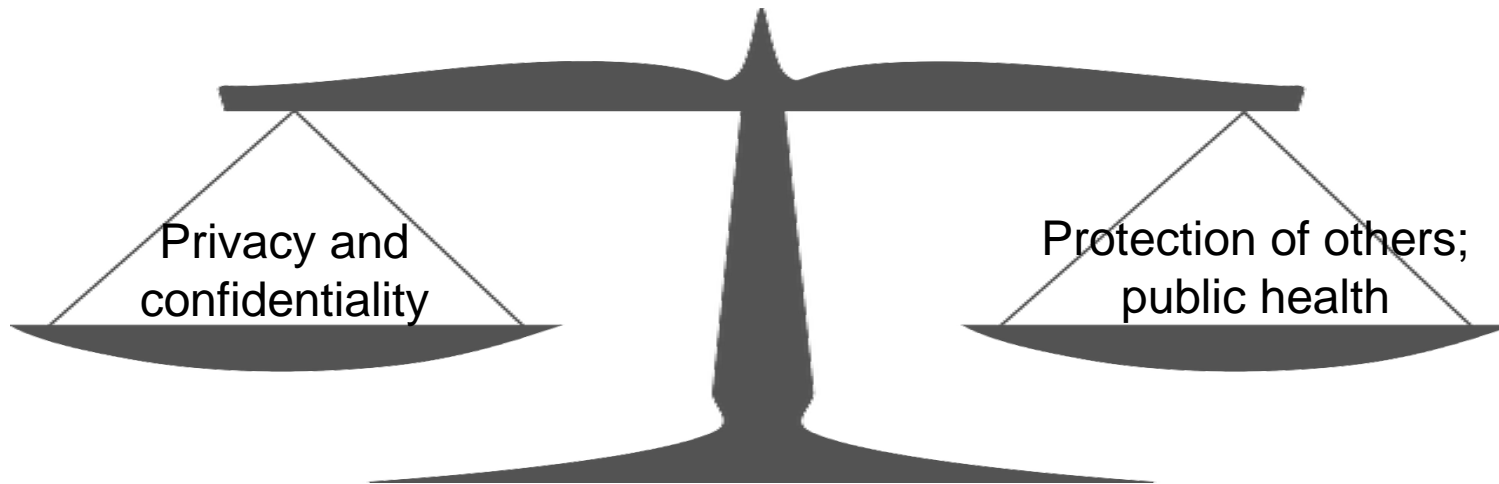




II. Dealing with the complex legal environment and ethical dilemmas

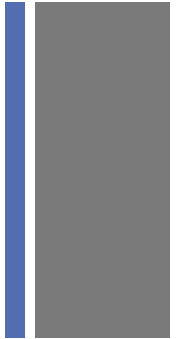


- The duty of confidentiality is central to providing STBBI-related services, but it is *not* absolute and will be balanced with other interests such as the protection of others or public health.



- These competing interests can sometimes be a source of difficult legal and ethical dilemmas for service providers.

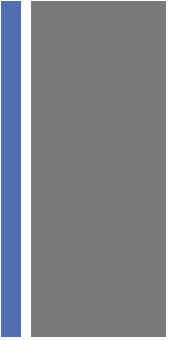
+ Barriers to disclosure of HIV status



- **What factors may affect a person's capacity to disclose their HIV positive status and/or take precautions to reduce risks of transmission to their sexual partner?**
 - Fear of rejection
 - Power imbalance within relationships
 - Stigma and discrimination
 - Other?

+ Sex, disclosure, STBBIS and the criminal law

- Under Canadian criminal law, people living with HIV have a legal duty to disclose their HIV-positive status to their sexual partner when they engage in sex that poses “**a realistic possibility of HIV transmission**” (which is interpreted by the courts).
- Most often, people are charged with aggravated sexual assault for not disclosing their status, even where *no* transmission occurred and they had *no* intention to harm their partners.



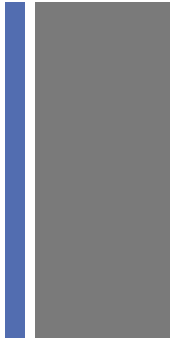
+ Current state of the law



SUPREME COURT OF CANADA

- The law might evolve or be applied differently depending on available medical evidence in a particular case. Based on the current state of the law, it is safest to assume that people living with HIV have a legal 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 (less than 1500 copies/mL).
- The law is not settled when it comes to other STBBIs.

+ HIV criminalization

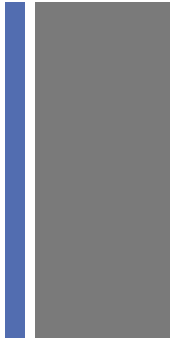
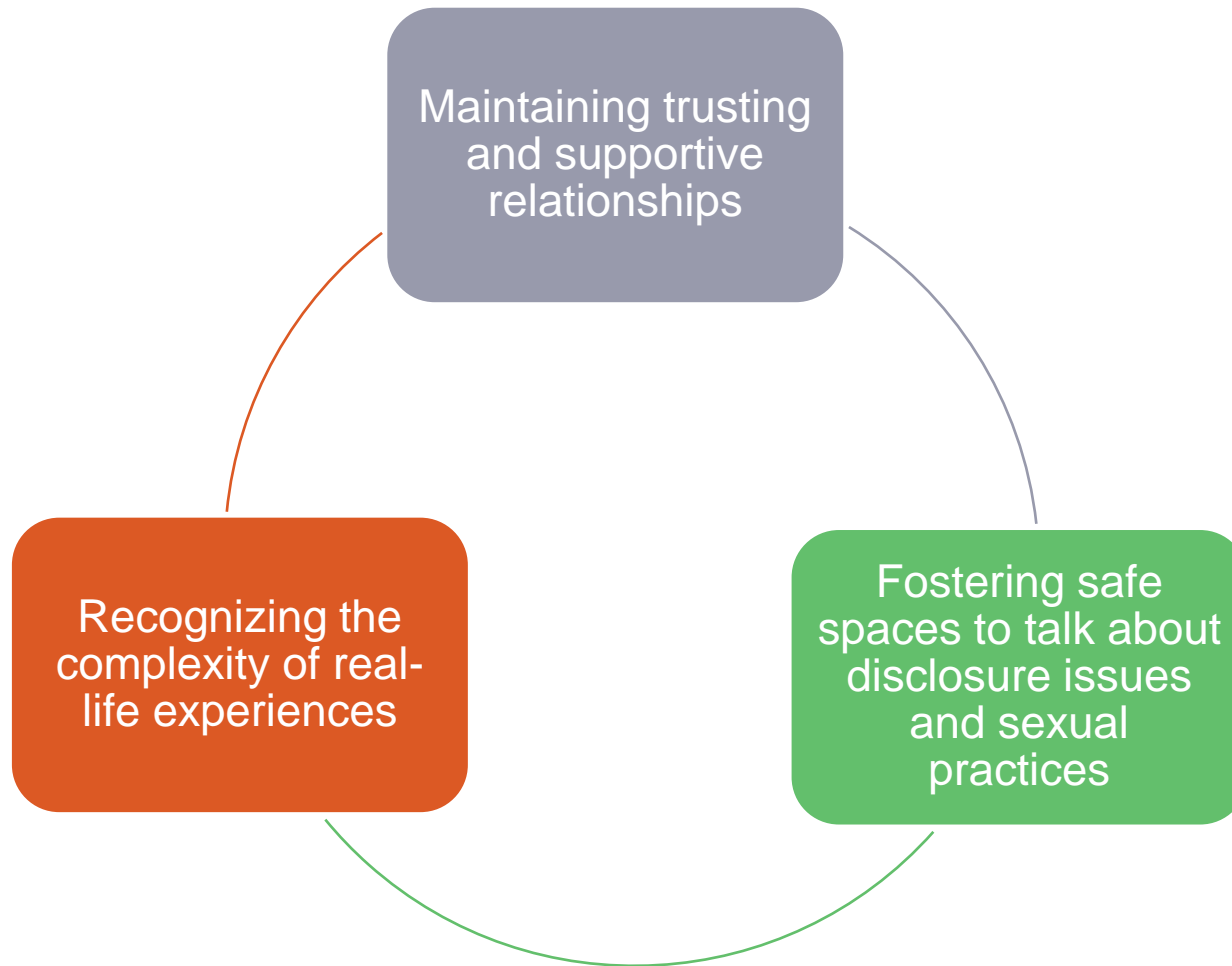


- More than 180 people have been charged for not disclosing their HIV status in Canada.
- Criminal prosecutions have very serious repercussions for people living with HIV and for public health more generally. They
 - provide a potential disincentive to get tested;
 - may discourage HIV-positive people from accessing HIV prevention resources, for fear that information they share about risky behaviour could be used against them; and
 - increase HIV-related stigma.

+ Discussing HIV criminalization with clients

- It is important for people who are HIV-positive (or seeking HIV testing) to know about the law so they can make informed decisions about their lives.
- Service providers should first determine whether there are mental or emotional health issues or any language barriers that may prevent their clients from fully understanding the law.
- Keep in mind the impact such discussions can have on clients, given how stigmatizing and harsh the current law is.
 - e.g. people who have just been diagnosed with HIV might not be in a position to receive such difficult information – it might be better to leave that important discussion for a follow-up appointment.

+ Keep in mind



+ The role of service providers



- Provide care and counselling to their clients
- Provide general information about the law and requirements to disclose HIV status under both public health law and criminal law
- Provide clients with written materials on the criminal law and HIV from reliable sources and appropriate referrals
- Work with their clients to promote overall health and well-being
- Minimize the adverse or negative effects of disclosure if the clients choose to disclose their status



- Service providers cannot provide legal advice
- There is no obligation to report a crime to the police or provide the police with information about a client (unless required by a warrant or if it involves a child in need of protection)
- There is no obligation to inform clients about their possible option to press charges against a sexual partner who may have exposed them to a risk of HIV (or other STBBIs)
- Service providers should not go to the police unless it is absolutely necessary

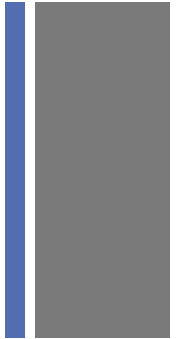


HIV criminalization and record-keeping

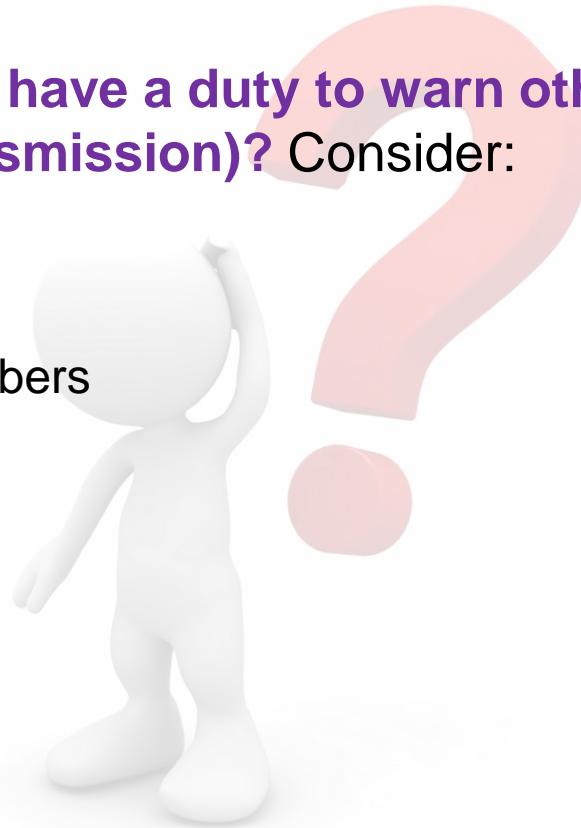


- Client's medical records are often used in criminal investigations for alleged HIV non-disclosure. Appropriate note-taking may require service providers to balance:
 - Keeping records in accordance with the generally accepted standards of practice of their profession.
 - Their interest in protecting their clients.
- When responding to a search warrant or subpoenas, service providers should
 - consult their organization's policy if one exists;
 - consult with the appropriate persons before taking any action; and
 - inform their clients and seek legal advice as soon as possible upon receiving a warrant or subpoena.
- Protecting client confidentiality should mean turning over **as little as is required** under the warrant. Steps can also be taken to protect client's confidentiality.

+ “Duty to warn”

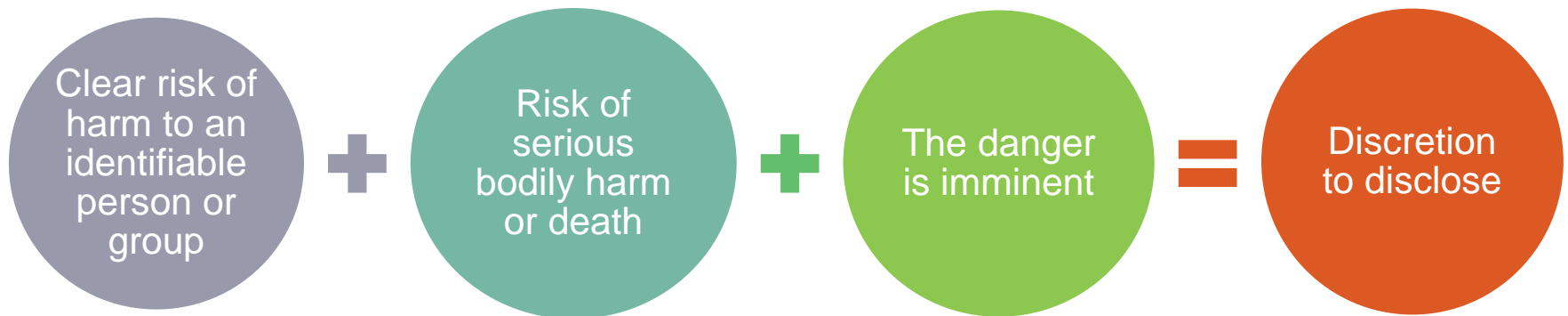


- **Do service providers have a duty to warn others at risk of harm (i.e. STBBI transmission)? Consider:**
 - Intimate partners
 - Family members
 - Other community members



+ Discretion to disclose

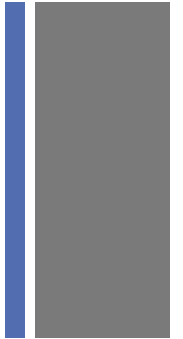
- There may be exceptional circumstances where service providers feel compelled to intervene in order to prevent harm to another person.



- Regulated professionals usually have laws, regulations or policies specifying when and how client confidentiality *may* be breached — including to protect a specific third party or the public.



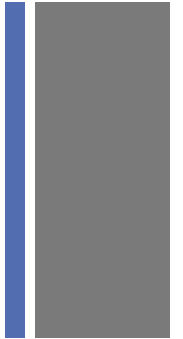
Exercising the discretion to disclose



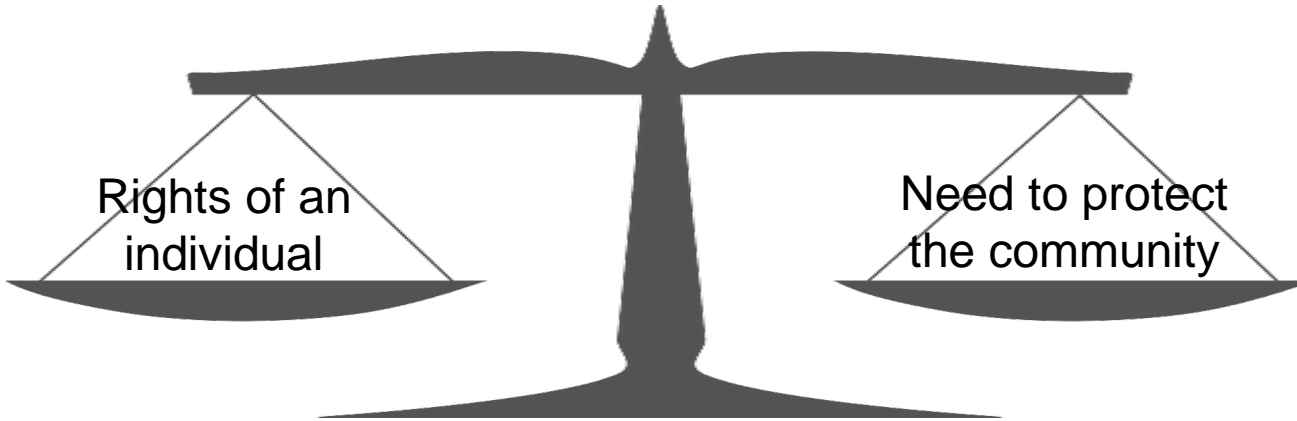
- In any circumstance, a decision to take action must be **carefully thought through**.
- Service providers should limit, as much as possible, any breach of their clients' confidentiality.
- Keep in mind that stigma, especially related to HIV and some marginalized groups, can influence perceptions of risks and of the need to intervene — especially in the current context of HIV criminalization.
- Service providers should record the reasons for their decision and **inform their clients** of any action to be taken if it breaches confidentiality.
 - Note that the client should be given reasonable notice *before* action is taken, unless this is not practical under the circumstances.

+ Protecting public health

- The powers and procedures of public health authorities in relation to HIV and other STBBIs vary among the provinces and territories, but they can include coercive interventions such as
 - Involuntary disclosure to a third party
 - the issuance of a written order instructing a designated person to take, or refrain from taking, any action that is specified in the order (e.g. an order instructing an individual to refrain from engaging in sex without a condom).



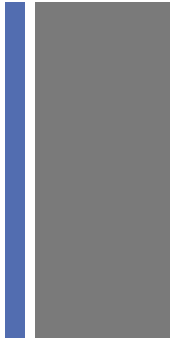
+ Finding a balance



- Important to consider the voluntary measures that have already been undertaken and assess risks of transmission based on the most recent and accurate medical evidence.
- Coercive interventions can reinforce stigma and discrimination against targeted groups.
- Generally speaking, the “**least intrusive, most effective**” graduated approach to interventions should always be followed.

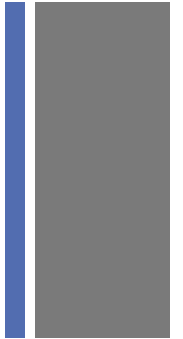


Useful resources



- **CPHA info sheet** — *Stigma, privacy and confidentiality*, 2016.
- **HIV disclosure and the law** — See Canadian HIV/AIDS Legal Network et al., *HIV Disclosure and the Law: A Resource Kit for Service Providers* at <http://www.aidslaw.ca/community-kit>
- **HIV disclosure and the criminal law** — See Canadian HIV/AIDS Legal Network, *Criminal Law & HIV Non-Disclosure in Canada*, at <http://www.aidslaw.ca/site/criminal-law-and-hiv/>, and watch a series of videos about HIV and the criminal law at www.youtube.com/aidslaw (in English and French).
- **HIV criminalization and its implications on nursing practices** — See Canadian Association of Nurses in AIDS Care (CANAC) and CATIE, *Legal and Clinical Implications of HIV Non/Disclosure: A Practical Guide for HIV Nurses in Canada*, 2013.
- **Testing and human rights** — See B.C. Civil Liberties Association, *HIV Testing Handbook: A Guide to Your Rights*, 2012.
- **HIV disclosure in health care settings** — See the Canadian HIV/AIDS Legal Network series of info sheets, *Know Your Rights*, available at <http://www.aidslaw.ca/site/kyr/> (available in English, French, Arabic, Chinese, Punjabi, Spanish and Tagalog).
- **Privacy legislation in Canada** — See Office of the Privacy Commissioner of Canada, *Privacy Legislation in Canada* fact sheet at https://www.priv.gc.ca/resource/fs-fi/02_05_d_15_e.asp (updated May 2014).

+ Thank you for your participation!



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