HIV Disclosure Guide
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*The resources listed in the “Resources” section of this document helped in creating this guide.*
What is “HIV Disclosure?”

“What disclosure” is the personal experience of communicating to another individual or group of individuals that you are a person living with HIV.

**HIV disclosure can/be:**

- Affect a person’s life
- Unhelpful
- Harmful
- Stressful
- Supportive
- Empowering
- Positive

**HIV disclosure is affected by:**

- Health and capacity (Mental, emotional, physical, social, spiritual)
- Supports (Mental, emotional, physical, social, spiritual)
- Access to health care (Testing)
- Community visibility
- Stigma
- Discrimination
- Oppression
- Education
- Misinformation
- Immigration
- Citizenship
- Culture
- Age
- Race
- Sex
- Gender (Identity, expression)
- Orientations (Romantic, sexual)
- Relationships
- Violence/Abuse
- Disability
- Religion/Spirituality
- Substance use
- Incarceration
- Laws (Disclosure; Duty to report)
- Class
- Social safety net
- Employment/Unemployment (Job security, working conditions)
- Income
- Poverty
- Food Insecurity
- Housing
Types of HIV Disclosure

Different reasons why someone will disclose their HIV include:

1. **Instrumental Goals:** Gain information and seek emotional and practical support, find relief from the stress of harbouring a secret, reduce isolation, and to educate others and share their experience.

2. **Identity Goals:** Non-disclosure of HIV to avoid stigma, discrimination, loss (family…), and maintain sense of self and safety. Cultural norms could dictate the disclosure affecting not only the individual but also the family. Individuals may feel low self-esteem, feel shameful or guilty. Disclosure of HIV is done to avoid involuntary or second-hand disclosure that may affect them more.

3. **Relational Goals:** Making the choice of disclosure or non-disclosure based on maintaining a relationship, whether or not the information would harm the individual, or having concerns the disclosure may result in a rejection.

HIV disclosures may be directed to:

- Acquaintances
- Friends
- Family
- Pets/Animals
- Service providers
- Employers
- Co-workers
- Community (Person related)
- Public (Everyone)
- Sexual partners

HIV disclosures may happen during:

- Conversations
- Intakes
- Check-ins
- Accessing services
- Testing (sexual health)
- Filling out forms (Agency forms, government forms)
- Research and Data Collection

Continued on the next page...
Types of HIV Disclosure

Disclosure of a person’s HIV may happen:

- **Voluntarily** (with the person’s knowledge and/or consent):
  1. **Everyone/Full Disclosure**: Individuals choose to disclose for social, political or educational reasons.
  2. **Selective individuals (Most common)**: Individuals assess each situation before disclosing. They open up to people with whom they have meaningful relationships, who can keep their secret or who can help them with regard to their health. Some external factors can facilitate selective disclosure, such as transmission risk to a partner through sexual contact.
  3. **Secret**: Disclosure to a very small number of people who will keep the information strictly confidential. Often, the confidant is someone’s partner or parent. With this type of disclosure, the individual may feel alone and isolated.
  4. **No One**

- **Involuntarily** (without the person’s knowledge and/or consent):
  1. **Testing**: HIV is a reportable infection in all Canadian provinces and territories, meaning that when an individual tests positive for HIV, the test result is reported to the provincial or territorial public health authorities. Information is also sent to the public health office of that individual’s residence; if someone was going to university in Guelph and was originally from Toronto, both public health locations would receive this information. However, if an individual chooses to do non-nominal and/or anonymous testing and does not give out contact and/or other personal information this process cannot be completed (if an individual receives a non-nominal or anonymous HIV rapid test they also have the option of doing a non-nominal or anonymous “confirmatory test” to confirm they are living with HIV). Most healthcare providers prefer to get a name and/or contact information to later on refer that individual to additional support if the test comes back reactive; if the test is non-nominal or anonymous the healthcare provider cannot follow-up. In these cases, individuals are always encouraged to come for a follow-up appointment.
  2. **Entering Care**: When an individual enters care and receive anti-retroviral therapy treatment, this information is then reported to the proper public health authorities.
3. **Contact Tracing:** Public health nurses give the individual a chance to disclose their HIV diagnosis with past or present partners. If they are not able and/or do not wish to make contact a public health nurse can contact the partners on their behalf after gathering the names of the partners; the name of the person living with HIV will be kept confidential. The nurse will suggest to the partner(s) that they have come into contact with a person living with HIV and suggest getting tested. This can become an issue when a partner thinks they have been in a monogamous relationship with their spouse, but receive this information. It should also be noted that public health does not do international contact tracing (will not contact individuals in Europe, Cuba, etc.).

4. **Immigration:** Individuals who are applying for permanent residence in Canada, as well as certain individuals applying for temporary residency, will be asked about their medical history on their application forms. Applicants will also be required to undergo a medical examination which includes an HIV test. The HIV-status of many applicants will therefore be known to Citizenship and Immigration Canada. Applicants in the Family Class or Dependent Refugee Class (i.e., those who are sponsored to come to Canada) should be aware that if you are sponsored by your spouse or partner and you test positive for HIV, Citizenship and Immigration Canada (CIC) will give you 60 days to tell your spouse or partner that you are HIV-positive, or to withdraw your application. If you don’t withdraw your application, CIC will notify your spouse or partner of your HIV-positive status after the 60-day deadline. Your spouse or partner will be given an additional 60 days to decide to withdraw or maintain sponsorship. If your spouse or partner doesn’t choose to withdraw sponsorship, your application will proceed normally. In these situations it is safer to assume that CIC has not contacted or will not contact your spouse(s) and/or partner(s) to notify them of the HIV status given the criminalization of HIV non-disclosure and new legal implications under the Canadian government; an individual could be charged in the future.

5. **Legal Cases**

6. **Accident/Gossip**
THE STAGES OF ADAPTING TO LIFE WITH HIV

Shock

Denial

“’I’m in shock.”
“’This is a total shock to me.”

“’It’s not true!”
“’No, not me!”
“’This can’t be happening!”
“’I’m dreaming, this is a nightmare!”

“Why me?”

Anger

Bargaining

“’Fine, I have no choice but to deal with it, but…”
“’OK, it’s happened to me, but…”
“’If I get better, I promise that…”
“’Give me another chance!”

Depression

“’I will never be the same.”
“’I’m all alone, no one cares, my life is over.”

Acceptance

“’I’ve accepted what has happened to me and I am moving forward.”

Integration

“’I’m learning to live with HIV. I’m finding new purpose in my life.”
Disclosure is a lifelong, cyclical, and reoccurring process. Although this process is displayed in a linear format, it should be noted that previous steps can be revisited and reoccur along someone’s disclosure journey (ie. Someone at the ‘Planning’ stage may need to revisit ‘Education’ and/or ‘Recovery & Support’).
Recovery & Support
- Trauma (A result of seroconversion, or associated with means of infection/past)
- Emotional regulation exercises
- Internalized stigma/serophobia
- Listen
- Normalize/Validate/Affirm Feelings
- Referrals (Medical, social, peer support groups)
- Contact tracing (done during next appointment or sooner if there are more partners)

Education
- HIV/AIDS 101 (Transmission, treatment)
- Safer sex 101 (STIS, barriers, prevention tools, etc)
- Disclosure, legal implications, rights, and responsibilities (HALCO) [No legal advice]
- Offer guidance (Disclosure preparation, planning…)

Preparation
- SMART Goals
- Disclosure list/Disclosure map
- Considerations
- Identify supports
- Find resources/handouts/referrals for your recipient
- Identify limits and boundaries

Planning
- SMART Goals
- Disclosure tools/activities
- Content
- Safety plan (x3)
- Review the plan (let the individual lead the conversation)
- Set a follow-up date (on day of disclosure or later)

Disclose

Follow-up
Emotional Regulation Exercises

- “Ground” yourself:

- Visualizations:
  - [http://hpnc-online.org/family-relationships/families/managing-emotions/focus-calming-grounding-activities-pdf](http://hpnc-online.org/family-relationships/families/managing-emotions/focus-calming-grounding-activities-pdf)

- Breathing exercises:
  - [http://www.anxietycoach.com/breathingexercise.html](http://www.anxietycoach.com/breathingexercise.html)
  - [http://hpnc-online.org/family-relationships/families/managing-emotions/focus-calming-grounding-activities-pdf](http://hpnc-online.org/family-relationships/families/managing-emotions/focus-calming-grounding-activities-pdf)

- Counting (To or backwards from a certain number… 10 or 100)

- Communicating with friends

- Journaling

- Drawing

- Painting

- Colouring

- Puzzles

- Music

- Moving your body (exercising, walking, rolling, stretching…)

- Walking backwards

- Leaving the space; separate yourself from the trigger

- Meditation

- Sitting in silence

- Post-Self-care (After experiencing emotions (with more intensity then you are used to) it is important for you to take time for yourself to rest, relax, and heal)

- Debriefing with someone (friend, family, healthcare provider….)
Preparation

- **SMART Goals:**
  - These goals can be used to help build a plan around key themes of safety, and motivation. Is my disclosure plan...:
    1. **Specific** (Do I know what I want to communicate? When and where will I communicate this information?)
    2. **Measureable** (Will I be able to tell if the individual understands my disclosure? How will I know they understand?)
    3. **Attainable** (Will I be able to carry out my disclosure plan?)
    4. **Relevant** (Will my plan help me on the way to my goal of disclosure?)
    5. **Time Oriented** (Will I be able to complete my disclosure soon? Do I have a timeframe that fits my life and schedule?)

- **Disclosure list/Disclosure map** (Who do I want to disclose to (Now [Present], later [Future], never)? Who do I need to disclose to? Who am I ready to share this information with? Why do I want them to know? What’s the goal of disclosing?)

- **Considerations** (Explore pros & cons/disclosure affects on dependents/children/adolescents/immediate family. Have I tried to determine what the recipient’s(s’) attitudes/views towards HIV are? How will disclosing affect me? How will it affect the people I tell? Am I ready for different possible responses? Will I be able to answer questions? Am I ready to tackle potential misconceptions? Do I need to be concerned about the safety of others (dependents)? Can I support myself and any dependents if kicked out? Am I able to get away if the situation turns violent? Do I have support?)

- **Identify supports** (Who can be there when I need someone reliable? Who can I trust? Who has been a good support in the past? Family, friends, peers, healthcare providers… These supports can be later selected for specific situations)

- **Find resources/handouts/referrals for your recipient** (Find relevant information about HIV that is accessible for certain recipients you are disclosing to; everyone accesses, understands, and interprets information differently! Find methods that best suit them for an easier process. Ask a healthcare provider or friend for help finding this information)

- **Identify limits and boundaries** (Create a list of things you are comfortable sharing about you and HIV. You can draw from these when planning individual cases)
The People in My Orbit

- Using the “The People in My Orbit” activity sheet 1; Grouping by Individuals and “The People in My Orbit” activity sheet 2; Diagram, the participants are asked to list the people in their orbit with whom the issue of disclosure may come up. You can use the “The People in My Orbit” activity sheet 1; Grouping by Individuals to let individuals list the people in their orbit first and then sort them into the diagram.

Within the various concentric circles, the participants are asked to:

1. Indicate in green, in the upper semicircle, the person(s) (or their first names) who know about their HIV positive status.

2. Indicate in red, in the lower semicircle, the person(s) (or their first names) who don’t know about their HIV positive status or to whom they do not wish to disclose their status.

3. Circle in red, in the upper semicircle, the person(s) (or their first names) who are not handling the situation well.

4. Circle in blue, in the lower semicircle, the person(s) (or their first names) they would like to tell.

5. Using blue asterisks (*) evaluate the extent of the moral obligation they feel to disclose their HIV-positive status for each of the people identified
   - * low moral obligation
   - ** medium moral obligation
   - *** high moral obligation

6. The facilitator asks the participants to put the people in their orbit in the various concentric circles, according to how important they are to them (the closer a person is to the centre, the more important that person is in their life).
   - To illustrate, the facilitator does the activity on the board using the sample version of the “The People in My Orbit” activity sheet 2; Diagram.
   - The facilitator then encourages the participants to do the exercise themselves. To keep the activity simple, the participants need only list one or two people in each circle.
   - Once everyone has completed the exercise, the facilitator leads a group discussion and asks the participants about the people in their orbit.

Disclosure List/Disclosure Map

- Invite the participants to reflect on the “people in their orbit”:
  - “Are you more “red” (secretive) or more “green” (open) when it comes to disclosing your status?”
  - “How much has the issue of disclosure come up in your life?”
  - “Are the people you have told the most important people in your life or people you really trust, or are they more people you aren’t that close to?”
  - “When you have shared your status with people, did it generally go well?”
  - “Are there people who are important to you that you haven’t told?”
  - “Of those you haven’t told, whom would you like to tell?”
  - “Of those you haven’t told, whom would you prefer never to tell?”
  - “What do you think makes these two groups different?”

- The concentric circle exercise is a great way for the participants to visualize all the people who are gravitating around them, as it provides a true picture of the configuration of their social network.

- This exercise also allows them to list the people with whom they have daily interactions. By putting an image of themselves inside this network, it becomes easier to see the extent to which disclosure is an issue within their network. It also allows them to see whether the people they have told are the people who are most important to them and with whom they have good relationships, or the opposite.

- The facilitator asks the participants what they got out of the activity on the people in their orbit and discusses with them the moral obligation they feel to disclose their HIV-positive status:
  - Do you feel morally obligated to disclose your status to certain people (e.g., “I feel like I should tell,” “I feel like I have to tell,” “I feel like it is my duty to tell”)? Why do you feel this obligation? Why would it be/is it important for you to tell certain people? Why do you feel/did you feel that telling certain people was the right thing to do?
  - Conversely, are there people whom you do not feel morally obligated to tell? Or people whom you feel morally obligated not to tell? What can you tell us about your relationship with these people?

Disclosure List/Disclosure Map

- Friends
- Family
- Partner(s)/Lover(s)
- Service Providers
- Community Members
- Professional/Work

Disclosure List/Disclosure Map

**DISCLOSE**

**Green**: The person knows and is dealing with it well.

**Red**: The person doesn’t know and I don’t want them to know.

**Green** with a **red circle**: The person knows but isn’t dealing with it well.

**Red** with a **blue circle**: The person doesn’t know and I want them to know, but I don’t know how to tell them or can’t.

- *Low moral obligation*
- **Medium moral obligation**
- ***High moral obligation***
SMART Goals:
These goals can be used to help build a plan around key themes of safety, and motivation. Is my disclosure plan...:
1. **Specific** (Do I know what I want to communicate? When and where will I communicate this information?)
2. **Measureable** (Will I be able to tell if the individual understands my disclosure? How will I know they understand?)
3. **Attainable** (Will I be able to carry out my disclosure plan?)
4. **Relevant** (Will my plan help me on the way to my goal of disclosure?)
5. **Time Oriented** (Will I be able to complete my disclosure soon? Do I have a timeframe that fits my life and schedule?)

Disclosure tools/activities:
- Create a letter for when you are disclosing (Disclosing can be hard and it’s okay to have what you want to communicate in your hands so you don’t forget to mention something)
- Have a hard copy of your safety plans (x3) for review
- Scenario exploration/facilitated communication (Practice/role play your disclosure or possible responses that may happen whether negative or positive, work on your writing/communication skills regarding disclosing, build your capacity and confidence)
- Specific programs or workshops (Sharing Together for Life...)
- Resources/handouts/referrals

Content:
- Specify limits and boundaries for the situation. You do not need to answer questions that make you feel uncomfortable or you do not give consent to (“I cannot answer that now, but maybe in the future,” “I will not answer that question it makes me feel uncomfortable,” “Please do not make fun of my HIV. It is something that is serious to me and many others.”)
- Specify confidentiality (“I am slowly telling individuals about my HIV, please allow me to communicate with them. Do not share this information with others until I communicate to you it is alright.”)
- Do not assume they know you are living with HIV. Be direct, brief, and clear (“I am a person living with HIV,” “I have HIV.”)
- Avoid jargon/confusing communication; keep communication accessible
- Ensure you are able to educate them on the basics of HIV, if you are ready, or bring resources/handouts/referrals (Transmission...
Planning

**Disclosure/Safety Plan (x3):**

When creating a safety plan, it’s important to have multiple plans pre-made so you always have other options if something happens; making three plans is a great first step! When making your safety plans consider the following:

- **Recipient(s)** (If in person; who is around? Do I feel comfortable around these people; do I want all those people to know about my HIV? If digital; who can access this information?)
- **Mood of recipient(s)** (Will the person be responsive to my disclosure? Are they upset, angry, or experiencing other emotions that may affect my safety or their ability to take in my disclosure? Should I check with them to make sure they are still feeling in a position to have a safe conversation?)
- **Medium** (Phone, email, text, letter, face-to-face/in-person… What feels safest? What works best for YOU?)
- **Setting** (Where will we meet? Do I feel safe in this location? Is this an open or closed location; which would I prefer and which is safest for me? Are there people around to help me if I need it? Can I get out/leave if my safety is threatened? How will I get there? Will I be able to leave independently or with the help of a reliable friend if I need to? If I am emotional or triggered, is this a safe mode of transportation for me?)
- **Time** (Is this a good time of day? Is it too early/too late? Will the timing affect people being around in my location, my support system, my transportation, or other aspects of my safety? Will the timing affect the mood of the recipient I am disclosing to?)
- **Support** (What supports do I have access to? What role will these supports take in my disclosure plan?)
  - **Pre-Support** (Discussing your disclosure/safety plans and feelings about disclosure, getting resources/handouts/referrals for my recipient, getting a ride…)
  - **Mid-Support** (Bring a friend, disclose in the presence of a health care provider…)
  - **Post-Support** (Will I have a ride home/to a safe location, if triggered contact a healthcare provider or friend, debrief the experience with a healthcare provider or friend…)
- **Reward** (HIV disclosure is a big deal. How are you going to reward yourself for your disclosure? You deserve a reward! Pick something immediate whether it’s buying yourself a cookie/drink/treat, making yourself a nice dinner, having a movie night, or even patting yourself on the back. You deserve recognition)
- **Self-care** (How am I going to take care of myself after the disclosure? How can I make sure my emotional, mental, physical, social, and spiritual health are alright and taken care of? What resources do I have access to for ensuring my health in these areas (tools, activities, people)?)
- **Debrief** (Talk to a friend or healthcare provider; What did the disclosure look like? What went right? What went wrong? What’s going on right now? How do you feel? What can you do differently to build a better plan for next time?)

- **Review the plan(s) (let the individual lead the conversation)**
- **Set a follow-up date, time, and location (on day of disclosure or later)**
Considerations for Employees, Peers, Volunteers (including Board Members), and Students

- Discuss participants’ roles in disclosing to at-risk partners. Offer resources or to witness and document an individual’s disclosure of their HIV to another individual in case notes.

- Inform people living with HIV they may not wish to discuss specific circumstances of having unprotected sex or engaging in other possible modes of HIV transmission, but instead using hypothetical narratives to disclose certain forms of information (ex: “I had condomless sex with someone and did not disclose my status.” vs. “If a person living with HIV were to have condomless sex with someone without disclosing their status, what information should they know?”). This may limit ability to work with the individual.

- Legal information can help a client understand the law and their rights, but it is general. Legal advice is about a client’s specific situation. It is meant to help a client decide what to do. Employees, volunteers (including Board Members), and students will not give legal advice to participants, nor will they give personal opinions regarding any related circumstance surrounding HIV disclosure or the overly broad criminalization of HIV non-disclosure.

- Use the terms “may” or “might” as opposed to affirmative/certain statements (ex: disclosing to your partner in front of a counselor might help prove HIV disclosure).

- All disclosure situations can have some level of legal implication. As a result, it is appropriate to provide referral information to the HIV & AIDS Legal Clinic Ontario (HALCO).

- Enforce consistency with the Personal Health Information Protection Act (PHIPA 2004) and Confidentiality Agreement.

- Record-keeping requires balancing the need to keep records in addition to protecting client confidentiality given the risks of data breaches and involuntary disclosures in the cases of search warrants and subpoenas.

- Staff will discuss with Executive Director anytime there is uncertainty of the level of detail or content to include in client records related to HIV disclosure.

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Considerations for Employees, Peers, Volunteers (including Board Members), and Students

- You may wish to mark case notes with a header or watermark that reads “Private and Confidential.” This may help you should you ever need to assert privilege in the cases of search warrants and subpoenas.

- The Executive Director will be notified immediately of potential controversial or politically contentious situations relating to HIV disclosure as they relate to employees, service users, volunteers (including Board members), and students—or of community events related to HIV disclosure that will affect the organization and its participants.

- Staff and volunteers may be forced to disclose client information to police under a search warrant or subpoena.

- Employees, volunteers (including Board Members), and students who are members of a professional body (like registered nurses and social workers) may have an ethical duty to disclose client information to prevent harm where a client’s behaviour places a known person at risk of HIV infection.

- Employees, volunteers (including Board Members), and students who do not take steps to prevent harm to a third party may be sued in civil court by anyone who suffers harm as a result of the failure to take those steps. But since no Canadian court has decided this issue, it is not clear whether the third party would win or lose the case. Find out if HIV transmission falls under the category of “immediate harm” in your professional body. In addition, employees, volunteers (including Board Members), and students may be sued in civil court by a client and found civilly liable if they disclose client information without consent, or without being compelled to do so under a search warrant or court order.

- Remember: it is an ORGANIZATIONAL decision to break confidentiality, not YOUR responsibility.

- ARCH believes HIV non-disclosure situations should be handled best by the individual themselves to allow to autonomy.
HIV and the Law

- Under current Canadian criminal law, people living with HIV are accountable for disclosing their HIV status before having sex if there is a “realistic possibility of HIV transmission” regardless of inquiry from their sexual partner(s).
- “Realistic possibility of HIV transmission”: Based on passed findings this can be dependent on the context, individual medical information.
- In R. v. Mabior and R. v. D.C. 1, the Supreme Court characterized even very small risks of HIV transmission as “a realistic possibility.”
- People living with HIV can be prosecuted for non-disclosure even if they had no intent to harm their partner. This is usually called the “criminalization of HIV non-disclosure.”
- Criminal charges for HIV non-disclosure can be laid (and have been in numerous cases) even if HIV is not transmitted.
- The Supreme Court of Canada has suggested that people who are aware they may be living with HIV but have not yet been diagnosed would have an obligation to disclose that possibility to sexual partners; not taking an HIV test does not necessarily mean you will be protected against prosecution.. Theoretically, this means that people could be charged for non-disclosure if the individual thinks they may be living with HIV and they do not disclose that possibility and/or as soon as they are aware of the possibility of living with HIV. As of today, we are not aware of any cases against people who have not received positive HIV test results.
- Remember that the criminal law is about disclosure. This means you should not be prosecuted for having sex (even if you do not use a condom and/or your viral load is high) if you have disclosed your status before sex and sex is consensual.
- The most common charge applied in cases of alleged HIV non-disclosure is aggravated sexual assault. A conviction for aggravated sexual assault carries a sentence of jail time (up to a maximum of life imprisonment) and registration on the Sexual Offender Registry. This is based on not providing the individual with enough information to properly consent and exposing someone to a “realistic possibility of HIV transmission” endangers life.
- Others are charged with crimes existing within the Canadian Criminal Code. Examples from past cases include administering a noxious substance, common nuisance, criminal negligence causing bodily harm, sexual assault, aggravated assault, attempted murder, and in one case involving alleged HIV transmission, murder.

Continued on the next page...
HIV and the Law

Based on the Supreme Court’s 2012 rulings:

- The court said in one case that a viral load of 1,500 copies or less of HIV per millilitre of blood counted as “low” – on the evidence in that case. The court specifically stated that the person did not have to prove that they had an “undetectable” viral load. An undetectable viral load means 40 or 50 copies or less of HIV, depending on the test used. What the courts will consider to be a “low” viral load may change in the future, so make sure you have the most up-to-date legal information.

Vaginal sex:

- No duty to disclose: Sex with condom use and “low” or “undetectable” viral load during sex
- Duty to disclose: Sex with condom use if viral load is higher than “low” or “undetectable”
- Duty to disclose: Sex without condom use regardless of viral load

Anal sex:

- No duty to disclose: Sex with condom use and “low” or “undetectable” viral load during sex. This is an assumption as the ruling may be similar to vaginal sex, though we cannot say for sure as the law is unclear on this.
- Duty to disclose: Sex without condom use regardless of viral load
- Duty to disclose: Sex with condom use if viral load is higher than “low” or “undetectable”

Oral sex:

- No duty to disclose: Oral sex with condom use and “low” or “undetectable” viral load during sex
- No duty to disclose: Rimming (analingus)
- Duty to disclose: “…we cannot say for certain, at time of writing, that oral sex without a condom and/or a low viral load does not require disclosure.”

“No risk” activities:

- No duty to disclose: Kissing, mutual masturbation…

Substance use:

- A person living with HIV who engages in substance use (sharing of materials) may have a legal duty to disclose, although no Canadian court has yet ruled on this issue.

Child bearing/Breast feeding:

- A parent living with HIV who risks transmitting HIV to a child during delivery and after the birth (e.g., by not informing health-care providers attending the birth, refusing preventive medications for the newborn infant, or breastfeeding) could potentially face criminal charges and/or intervention from child protection authorities; be open with your doctor. One individual was charged due to vertical transmission. In Canada, it is recommended to formula feed your baby as this is a no risk option for HIV transmission; it is recommended to not “mix feed” your baby via personal breast feeding and then mammalian milk (cow, goat, etc) and/or formula as this can increase risk of infection.
How to Avoid Being Charged with HIV Non-Disclosure

- The person living with HIV clearly disclosing before engaging in the activity that poses a “realistic possibility of HIV transmission”, and discussing the risk of HIV transmission and prevention options with all sexual and at-risk partners.

- Disclosing in front of a witness, such as a counsellor or health-care provider, who can ensure that the individual’s partner understands what the disclosure means and can document in a client-file that disclosure took place before the activity that poses a “realistic possibility of HIV transmission.”

- Having sexual and at-risk partners sign a document or make a short video indicating that they are aware that the person is living with HIV before engaging in the activity that poses a “realistic possibility of HIV transmission.”

- People living with HIV should keep copies of any documents or correspondence that can be used to show that disclosure took place before engaging in the activity that poses a “realistic possibility of HIV transmission,” such as letters, e-mail messages or chat-room dialogues. (Remember that anything you write in an e-mail, on a website or through social media may later be shared with others — be very careful when posting personal information online).

- Avoiding activities that may pose higher risk for HIV transmission, including vaginal and anal intercourse without a condom, and sharing substance use equipment (injection/inhalation supplies, etc).

- Working with a doctor to maintain a “low” or “undetectable” viral load. Individuals can ask their doctor to test them on a regular basis (for example, every three to six months) in order to establish a record of “lowered” viral load.

- Continue to take your anti-retroviral therapy/treatment (ART) medication as instructed by your doctor. This will also help to keep your viral load “low” or “undetectable.” In addition, following the instructions and not skipping doses for your medication will also prevent your body from becoming resistant to the medication. If you skip doses and are not taking your medication regularly, you could develop a resistance to your medication and your viral load could unknowingly begin getting higher.
HIV Disclosure Form

I, ____________________________ (printed name of partner), have had the following information explained to me by my partner (☐) and/or a healthcare provider (☐) and understand this information completely:

1. **HIV 101** (including, but not limited to, information on viral loads, CD4s, anti-retroviral therapy/treatment, and HIV transmission);

2. **Prevention tools for HIV transmission** (including, but not limited to, barriers [including, but not limited to, dental dams, condoms...], Pre-Exposure Prophylaxis [PrEP], Post-Exposure Prophylaxis [PEP]...);

3. **HIV transmission and any “realistic possibility of HIV transmission” in relation to the personal experiences between my partner and I** (including, but not limited to, sexual intercourse/outercourse, multiple partners, and drug use [by injection, inhalation, and/or other means of use]);

By signing below, I ____________________________ (printed name of partner) declare that my partner _______________________________ (printed name of participant) has disclosed that they are a person living with HIV to myself (____________________________ [printed name of partner]). I have had the above points (#’s 1—3) explained in full and understand them completely. I understand that I can access further education and support through HIV/AIDS Resources and Community Health, other AIDS Service Organizations (ASOs), and/or other qualifying healthcare providers (public health...) at any time for further education and/or clarification.

As a participant I, _______________________________ (printed name of participant), am aware that signing this document may not help me in a legal case involving HIV non-disclosure should my partner press charges; however, this document may present itself in a court of law as evidence of disclosing me being a person living with HIV to the individual partner as specified by name and signature below.

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<td>Partner’s Signature</td>
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*Note: Government name refers to the name the individual is registered under within a governmental context. Some individuals may be referred to by a different name that appears on their identification such as birth certificate, driver’s license, and/or health card other documentation.

*Note: This document is purposed for use/understanding between two individuals. If the participant has more than one partner, this document should be filled out between the participant and each new partner.
What to Do If Charged with HIV Non-Disclosure

- Contact a criminal defence lawyer. Talk to the lawyer before talking with anyone else to get the story of the incident straight before sharing it with other individuals.
- The Canadian HIV/AIDS Legal Network and HIV & AIDS Legal Clinic Ontario (HALCO) may be able to give suggestions of possible lawyers to contact.
- Anyone who is not a Canadian citizen, including permanent residents, with no immigration status, and/or a refugee may want to also contact an immigration lawyer; there may be a risk of being deported.
- Sharing basic information if contacted or detained by police (name, birth date…) is okay. The individual being contacted does not have to share more information until in the presence of a lawyer. Individuals have the right to speak with their lawyer in private without delay.
- The police can arrest the individual and put them in jail. They can apply for bail – to be released from jail until your case has been decided. If the court refuses to release them, they will have to stay in jail while their case is ongoing.
- An AIDS Service Organization or prisoner support program may be able to offer additional support.
- The individual’s picture, HIV status, other personal information, and the crime they are accused of committing may appear in a police press release, in the media and on the internet. Usually, criminal court trials are open to the public and the media.
- A lawyer can be hired to defend the individual in court. Depending on their income, legal aid may be able to help pay for the lawyer.
- If they plead guilty, or if the court decides they are guilty, they will almost certainly be sentenced to time in prison. They will have a criminal record. Their name may be put on a list of sex offenders. A DNA sample may be taken from them and placed in a data bank of convicted criminals.
- If the charges are dropped or they are found “not guilty” after a trial, they will be set free.
- A person with a criminal record may not be able to travel to some countries and they may not be able to get some types of jobs. If they are not a Canadian citizen, immigration authorities may be able to deport them.
How to Navigate a Subpoena

- A subpoena is a court order requiring a person to attend court to give evidence at a time and place stated in the subpoena. Under the Criminal Code, a court can issue a subpoena to any person who is likely to have material evidence about a criminal case (Criminal Code, sections 697 to 708) and bring the evidence in their possession or control that is relevant to the proceedings; this could include a client’s counselling records. A person who fails, without lawful excuse, to attend these proceedings is guilty of contempt of court, and the court can issue an arrest warrant for that person. ARCH will develop procedures to minimize the amount of information that must be disclosed when issued with search warrants and subpoenas.

- When served with a subpoena, it is recommended to take the following steps:

  - Contact the Executive Director as soon as possible; in-person, phone, text, email. The Executive Director should be present to speak with the police if need be and throughout the entire process.
  - In the event the Executive Director is not available, contact the Board President.
  - Consult the organization’s policy and guidelines on client confidentiality and record-keeping.
  - Contact the client and advise them of the subpoena. Suggest to the client that they seek legal advice. Provide appropriate referrals, e.g., a criminal lawyer, lawyer referral service, legal aid office, legal clinic, or legal advice service.
  - Call a lawyer to get legal advice.
  - Identify what exact information and documents are required by the court. A lawyer can help the organization to do this.
  - Locate the records (or portions of the records) and place them in an envelope or box and seal it. Write on the envelope or box: PRIVILEGE ASSERTED — DO NOT OPEN.
  - Work with the organization’s lawyer to prepare the defence of the assertion of privilege in court.
How to Navigate a Search Warrant

- A search warrant can be used by police officers in the investigation of criminal or other types of offences to look for and seize records, including counselling records. Note that the police are not to review the documents before seizing them or to browse through files to determine what might be relevant. ARCH will develop procedures to minimize the amount of information that must be disclosed when issued with search warrants and subpoenas.

- When the police demand a client’s counselling or other records such as HIV test results and medical files under a search warrant, it is recommended to take the following steps:

  □ Contact the Executive Director as soon as possible; in-person, phone, text, email. The Executive Director should be present to speak with the police if need be and throughout the entire process.

  □ In the event the Executive Director is not available, contact the Board President.

  □ Upon arrival, the police officer (or other peace officer) should identify themselves, provide identification upon request, explain the purpose of their presence, and provide a valid search warrant. In order to be valid, a search warrant must be signed by a justice of the peace or provincial court judge and dated.

  □ Ask to see the warrant and to receive a copy for your records. Examine the warrant to make sure a justice of the peace has signed it and that it relates to the records the police have asked for. Check the deadline that limits the length of time the police can use the warrant.

  □ Ask the police exactly what records they want.

  □ Consult the organization’s policy and guidelines on client confidentiality and record-keeping.

  □ The individual should immediately consult the appropriate resource persons (e.g., health record administrator, support staff) and wait for instructions on how to proceed.

  □ You may wish to call a lawyer as soon as possible to get legal advice before handing over the documents to the police. If not, then get advice as soon as possible after the police have left with the documents.

Continued on the next page...
How to Navigate a Search Warrant

- The person responsible (Executive Director) for coordinating a response in the event of a search warrant should:
  - Review the search warrant and make a copy of the document;
  - Verify the scope of the search warrant (what material is covered by the warrant);
  - Make copies of the original records (or portions of the records) under warrant; and
  - Ensure that the officer does not review the client records before seizing them.
- Support staff should locate the records (or portions of the records) for the police (which could be paper documents or computer files depending on what the warrant says) and place them in an envelope or box and seal it. Write on the envelope or box: PRIVILEGE ASSERTED — DO NOT OPEN.
- Tell the police: “I AM ASSERTING THAT THESE RECORDS ARE CONFIDENTIAL AND PRIVILEGED AT LAW.”
- Tell the police the name, address and telephone number of the organization's lawyer, if known.
- Give the records to the police. They will take them away.
- Call the client immediately. Advise them of the seizure and suggest that they seek legal advice providing appropriate referrals.
- If not already done, call a lawyer as soon as possible to get legal advice after the police have left with the documents.

* Asserting “privilege” is important because it buys the agency time and gives the client an opportunity to challenge the seizure by police. It is a legal action that demonstrates the organization is opposed to the search warrant and may challenge in court the seizure of the records and their use as evidence in a prosecution.

The Supreme Court of Canada has adopted a four-part test to determine whether, in any given case, there is a privilege that applies to prohibit confidential information from being disclosed and used as evidence in a court proceeding. In order to find that there is such a privilege, a court must be satisfied that:

1. the client disclosed the information in confidence that it would not be divulged;
2. the confidentiality must be essential to the relationship;
3. the community believes that the relationship should be protected and fostered;
4. disclosing the information would do more harm to the relationship than the benefit gained by
Sharing Together for Life: An Adapted Workbook

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Meeting 1: Welcome

Required Materials for the Meeting

- A logbook for each participant
- A binder/duo-tang for each participant
- A pen for each participant
- Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)

Print Outs (1 per participant):
- “Moral Commitment and Confidentiality Agreement: Activity Sheet”
- “Code of Conduct: Activity Sheet”
- “Appointment Card: Activity Sheet”

Introduction of the Facilitator

- The facilitator welcomes the participants and introduces themself: first name, pronouns, professional background, interest in the program.

Interest and Experience of the Participants

- The facilitator asks the participants how they heard about the program and what they hope to get out of it.
- The facilitator can also ask if they have ever participated in the program and, if so, what they got out of the experience.

Presentation of Program Components

- The facilitator explains the purpose and objectives of the program and presents:
  - the proposed number of meetings;
  - the approximate length of each meeting;
  - individual themes that will be discussed;
  - educational activities that will be carried out.

Objectives of the Program

- The program is designed to help participants become more proactive and thoughtful when it comes to the issue of whether or not to disclose their HIV-positive status and to help them...
  - realize it is possible to lead a full life with HIV;
  - recognize situations where the issue of disclosing their HIV status may come up;
  - evaluate potential issues surrounding the disclosure of their HIV status in various situations;
  - plan strategies related to the disclosure of their HIV status;
  - put to use their acquired knowledge in other situations where the issue of disclosing their HIV status may come up.

Welcome

Meeting Themes

- The program includes nine meetings (of around 3 hours each) on the following themes:
  - **Welcome**: establishing contact with the facilitator and the other participants in the group.
  - **Learning to Live with HIV**: the process of adapting to life with HIV
  - **Life Situations**: scenarios where the issue of disclosure or the secret may come up
  - **Controlling My Own Destiny**: possible consequences of disclosing one’s HIV status in various situations
  - **Sharing to Better Support Eachother**: disclosure strategies in various situations
  - **Secrets to Keeping Your Secret**: possible consequences of revealing one’s secret in different situations
  - **One, Two, Three, HUSH!**: strategies to keep one’s secret in different situations
  - **Participants’ Messages**: group mural and wrap-up of the program.

- The facilitator should explain to the participants that this isn’t group therapy but rather a discussion group that promotes learning, reflection and group discussions. It is a structured program, with predetermined objectives through which participants can pursue their own path.

- The facilitator should remind the participants that the program does not advocate that they should or should not disclose their HIV status to those around them. The purpose of the program is to allow them to share the experiences they have had when the issue of disclosing their HIV status has come up, to be more thoughtful and proactive when the issue of disclosing their HIV status arises in various situations, and to learn tools they can use to either disclose their HIV status or keep it secret, if that is their decision.

- The facilitator should explain to the participants that whatever they wish to share is up to them and that they can count on the group to be supportive and respectful.

- Finally, the facilitator will hand participants the “**Moral Commitment and Confidentiality Agreement**” and “**Code of Conduct**” sheets for them to fill out; a copy with their signature will be kept by both the participant and facilitator in a secure location.

Welcome

Moral Commitment and Confidentiality Agreement

You have the right to confidentiality and privacy by staff members, volunteers, participants and peers. All information relating to you as a participant must be treated as confidential. This includes all information that staff, volunteers, peers and participants obtain during the exercise of duties or attendance in services the organization provides. Information includes, but is not limited to, that which is obtained through written or verbal communication.

As a participant you do not have the property right to our records, only the right to protection of all information contained therein.

Your confidentiality is protected by staff members and volunteers based on professional, legal and ethical guidelines. Aside from sharing essential information with those involved within your circle of care*, breach of confidentiality is sanctioned only in circumstances where there is:

- Certain belief that harm will come to you or another individual;
- Suspicion or direct disclosure of child abuse or neglect;
- Upon written authorization of you the participant;
- Or in response to a court subpoena or required by law.

Confidentiality within group events and activities is a shared responsibility of all those involved, and is based on mutual trust and respect. Involvement in individual or group events warrants your respect and adherence to confidentiality guidelines. Breach of these terms may result in your suspension and/or termination of involvement within specific ARCH programs.

This Confidentiality Agreement is binding beyond your association with ARCH.

As a member of ARCH: HIV/AIDS Resources & Community Health, I acknowledge that my involvement in ARCH services is based on my recognition and continued adherence to confidentiality guidelines. I agree not to disclose information about anyone I come into contact with while receiving services from ARCH. This includes, but is not limited to, any information that may help identify another participant or peer of ARCH, such as, names, physical descriptions, contact details, as well as content of our interactions. I acknowledge that any misuse of information shall be considered a breach of confidentiality and will be cause for disciplinary action.

My signature indicates that I have read carefully and understand the Confidentiality Agreement and that I agree to its terms and conditions. I am aware that my refusal to sign this agreement will exclude me from participating in group activities. Furthermore, I am aware that intentional or involuntary violation of this agreement may impact my level of involvement in ARCH programs and services.

Name/Signature of Participant: ________________________ / ________________________

Date: ______________________________

*For the purpose of this Confidentiality Agreement, the term ‘circle of care’ refers to service provides who are involved in the provision of a participant’s health and well-being.
Welcome

Code of Conduct

I commit to being/recognizing:

- Respectful;
- Non-judgemental;
- Not imposing my personal values on someone else;
- Attentive and empathetic;
- Formally committed to maintaining confidentiality;
- Support the other participants;
- Owning my emotions, speaking in the first person (“I”);
- Explore the pros and cons of each situation;
- Sharing my strategies with the other participants;
- Help other participants’ develop their strengths;
- Letting everyone express themselves freely without interruption, impositions, and/or directing them;
- Showing up to meetings and/or letting the facilitator know I will not be able to attend when a circumstance arises;
- Everyone has the right to decide for themselves;
  - In certain contexts, KEEPING one’s secret is best;
  - In other contexts, REVEALING one’s secret is best.
- Everyone can find their own solutions;
- Everyone can answer these questions: Who to tell or not tell? When? Where? Under what conditions? How?
- Everyone can find solutions to deal with the negative or positive reactions of others;
- Everyone can find solutions to deal with being “outed.” Disclosure is a recurring issue in the life of every person living with HIV. Over time, a person living with HIV will have to keep evaluating disclosure-related issues as situations may change;
- Every person living with HIV goes through their own journey. An individual may become overwhelmed or upset on their journey of adapting to life with HIV and may experience a wide range of emotions related to their condition;
- Everyone deals with their HIV status at their own pace and in their own way;
- Participants will be allowed to share their experiences surrounding the issue of disclosure. Those who do are always treated with respect. Those who do not will also be treated with the same respect.

Name of Participant: ____________________________

Signature of Participant: ____________________________

Date: ____________________________

Welcome

Participants’ Preferences
- If it is an individual meeting, the facilitator asks the participant to indicate their availability and meeting time preferences. This way, the facilitator can create one or more groups based on each participant’s availability and preferences or choose meeting times that work best for most of the participants.
- If the meeting times have been predetermined, the facilitator can give each participant the “Appointment Card “activity sheet. This card indicates the title, location, time and date of each meeting.

Question Period
- Before continuing with the meeting, the facilitator asks the participants if they have any questions regarding their commitment to the program or the structure of the meetings and then answers them.
- The facilitator thanks the participants for their attendance and participation.
- Give the participants a few minutes to talk if they feel uneasy. Appointments can be scheduled for later on if necessary.
- If required, tell the participants about support contacts who would be happy to meet with them if they feel the need.

The Participant Binder/Duo-tang
- The facilitator will hand out a binder or a duo-tang to each participant.
- The facilitator will explain that the binder or duo-tang is meant to hold all the handouts and materials given to individuals over the course of the meeting. If individuals cannot bring the binder or duo-tang home with them, the facilitator can keep it with them in a secure location.
- If individuals bring their binder/duo-tang home with them, they must bring it to each meeting as some meetings draw from activities they have already completed in previous meetings.

1. “Welcome:”
   - Date/Time:___________________________
2. “Learning to Live with...:”
   - Date/Time:___________________________
3. “Life Situations:”
   - Date/Time:___________________________
4. “Controlling My Own Destiny:”
   - Date/Time:___________________________
5. “Sharing to Better Support Eachother:”
   - Date/Time:___________________________
6. “Secrets to Keeping Your Secret:”
   - Date/Time:___________________________
7. “One, Two, Three, HUSH!:”
   - Date/Time:___________________________
8. “Participants’ Messages:”
   - Date/Time:___________________________
   - Location:_____________________________

My First Page

- The facilitator presents several types of blank logbooks to the participants and asks them each to choose one.

- The facilitator explains that the logbook will serve as a reflection, tracking and learning tool during the meetings and that they can use it to do specific activities at home if they wish, providing they bring their logbook back to each meeting.

- The logbook can also be kept by the facilitator in a secure location.

- The facilitator gives each of the participants a logbook and a sheet of white or coloured cardboard. To complete their “first page,” the participants are asked to spontaneously answer this question:
  
  - “What would you like to get out of the workshops?”

- Encourage the participants to use their creativity and imagination. They can use drawings, scrapbooking, music lyrics, or even words or images cut out from a magazine to do the exercise.

- Encourage the participants to collect images, bits of writing or wrapping paper, phrases from magazines, ribbons and other materials at home, which they could use to create the pages of their logbook. The idea is to collect things they like and that reflect their feelings.

- As a follow-up to this exercise, the facilitator asks those who wish to share with the group what their first page represents.

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”

- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and logbook in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.
- Participants will be asked to bring in a photo or several photos to the next meeting that express how they feel about HIV (it can be a photo of anything).

Meeting 2: Learning to Live with HIV

Required Materials for the Meeting

- A logbook for each participant
- Participant binder/duo-tang
- Art supplies for each participant (scissors, glue, pencil crayons, various stickers, various magazines, etc.)
- A blackboard or flip chart; chalk or markers
- A pen for each participant

Print Outs (1 per participant):
- “HIV in images” support sheet
- “Annie’s Story: Activity Sheet”
- “The Stages of Adapting to Life with HIV: Activity Sheet”
- “The Stages of Adapting to Life with HIV: Activity Sheet; Note”

How I See HIV

- The facilitator tells the participants that they will discuss how they see HIV. These views can be negative, positive or neutral. Many factors can influence how people see HIV: the number of years they have been living with HIV, their experience with the HIV (few or no symptoms, the support and acceptance of those around them, experiences of rejection or discrimination, etc.), their attitudes towards HIV, etc.

- The facilitator reminds the participants that everyone has their own views of HIV; there are no right or wrong answers.

- The facilitator asks the participants not to comment on, criticize or judge others’ views.

- The facilitator asks the participants who brought an image to describe it to the group and explain how it represents how they see HIV. If there are participants who did not bring images, the facilitator can put some images on a table that represent various aspects of HIV (“HIV in Images” activity sheet). The facilitator then asks the participants to choose the image that best expresses what HIV means to them and, for those who wish to share, why it represents how they see HIV.

HIV in Images

- Show a variety of images to allow individuals to choose how they are feeling to reflect what stage they are in relation to HIV and HIV disclosure.

- These images can include scenery, action photos, movie, posters, magazine photos, stock photos, shapes, symbols, letters, feelings, colour samples, words, and/or numbers.

- Scaling questions (0—10) can be used to determine how strong an individual relates to their selection.

- Reflections and open-ended questions can be used by the facilitator to help the participant elaborate if the participant is interested.

Learning to Live with HIV

HIV in Images

Learning to Live with HIV

My Life Journey with HIV

- The facilitator reads Annie’s Story” activity sheet and asks the participants for their feedback.

- The facilitator then writes the stages of adapting to life with HIV on the board, referring to “The Stages of Adapting to Life with HIV” activity sheet.

- The facilitator asks the participants to answer the following question: “What does accepting your HIV-positive status mean to you?”

- The facilitator then writes keywords relating to what the participants have said next to “The Stages of Adapting to Life with HIV” activity sheet which were previously written on the board.

- After this activity, the facilitator reads the definitions of the words “Acceptance” and “Integration” (see next page) and draws connections, if any, with the participants’ statements that were written on the board.

- The facilitator then hands out a paper copy of the stages of grief after learning of a chronic disease (“The Stages of Adapting to Life with HIV” activity sheet).

- The facilitator then asks those who wish to share their experiences to do so one by one. The facilitator guides the exchange by asking the following questions:
  - “What did you feel when you learned that you had contracted HIV? “
  - “How did you process what you were being told?”
  - “What part of having HIV makes you the saddest? The angriest?”
  - “What part of having the disease concerns you the most?”
  - “How do you cope with HIV? How do you manage to live a good life with HIV? What are your secrets?”
  - “How do you envision the rest of your life?”

- The facilitator ends the exchange by thanking the participants for sharing.

- The facilitator reminds the participants that everyone comes to the point of accepting (or owning) their HIV in their own way and at their own pace, that this can be difficult, and that there is help out there to support them along their journey.

- The facilitator suggests that they should feel free to seek professional help if ever they need help coping with their HIV.

Learning to Live with HIV

Acceptance (ownership) Is...
- The person recognizes that they have contracted HIV.
- They recognize the fears associated with the disease and understand that it carries risks.
- They accept that HIV is part of their daily life; HIV is integrated (or “tolerated”).
- The person has redefined themselves as someone living with HIV; a chronic virus.
- They understand that they can no longer be the same person they were before and accept themselves as a person living with HIV but know that this not all they are.
- Moving beyond the initial shock allows them to see a future for themselves, even with the disease, and to want to keep on living.
- “Acceptance of a chronic disease means that the patient ‘owns’ it. It’s an attitude that reflects a lucid acceptance of a reality or situation that they are choosing to deal with so they can move forward and learn to live with their chronic disease.” (Translation of Giraudet quote, 2006, pg. 9)

Acceptance Is Not...
- Being OK with having HIV or giving in to the disease.

Integration (transformation) Is...
- The person makes the changes in their daily life that they need to make so they can lead a full life with HIV.
- At this stage, the person is striving to lead a balanced, healthy life with HIV and to find new meaning in their life.


Annie’s Story

Annie, age 35, learns that she has HIV; there is no cure. Annie leaves the doctor’s office, runs a few errands, goes home and calls her best friend to share the news with her.

While preparing supper, she explains to her friend that she will have to adapt to her new reality.

The next day, Annie goes to the offices of a non-profit organization that offers support services for women living with HIV and joins a support group whose first meeting will be held the following week.

She calls her family to give them the news, prepares herself to tell her employer the following week and does some online research to learn more about the disease.

Annie doesn’t crumble. She faces the situation head on, without ever getting angry or crying.

The truth is, Annie DOESN’T EXIST!

- The facilitator explains that when people learn they have contracted HIV, it is perfectly normal for them to be in shock and to feel like the rug has been pulled out from under them. They then go through other stages, in their own time, before coming to the point of acceptance (ownership). Few people react as Annie did and when they do, it’s because they suspected they were HIV-positive or were prepared for the news. Overall, this would be the exception.
THE STAGES OF ADAPTING TO LIFE WITH HIV

**Shock**
- “I’m in shock.”
- “This is a total shock to me.”

**Denial**
- “It’s not true!”
- “No, not me!”
- “This can’t be happening!”
- “I’m dreaming, this is a nightmare!”

**Anger**
- “Why me?”

**Bargaining**
- “Fine, I have no choice but to deal with it, but...”
- “OK, it’s happened to me, but...”
- “If I get better, I promise that...”
- “Give me another chance!”

**Depression**
- “I will never be the same.”
- “I’m all alone, no one cares, my life is over.”

**Acceptance**
- “I’ve accepted what has happened to me and I am moving forward.”

**Integration**
- “I’m learning to live with HIV. I’m finding new purpose in my life.”

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Learning to Live with HIV

Note: The Stages of Adapting to Life with HIV

- These stages are very common for people who are living with HIV or dealing with grief, although not everyone goes through them in this order or at the same pace. For example, a person may experience shock after denial.

- Going through a stage once doesn’t mean an individual won’t go through it again. For example, a person may feel angry again after coming out of depression.

- These stages are part of an indispensable process that leads people to accept the disease and integrate it in their lives.


**Sources:**

Learning to Live with HIV

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”

- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and log-book in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 3: Life Situations

Required Materials for the Meeting

- A logbook for each participant
- Participant binder/duo-tang
- Red, green and blue pencils, crayons or markers for each participant
- A blackboard or flip chart and chalk or markers
- The “game board” (optional if you choose to use this method during facilitation)

Print Outs (1 per participant):
- “Very Different Obligations: Activity Sheet”
- “Contextual Images: Activity Sheet”
- “The People in My Orbit: Activity Sheet 1; Grouping by Individuals”
- “The People in My Orbit: Activity Sheet 2; Diagram”

In What Situations?

- The facilitator asks the participants to think about different situations where the issue of disclosing or not disclosing their HIV-positive status may come up and to list them (e.g., in the workplace, among family members, in other relationships, with sexual partners, etc.).

- The facilitator writes the situations identified by the participants on the board.

- Other situations can then be added by the participants and the facilitator if they are not present (family life, love life, work life, medical setting, social life, etc.) within which the participants can list the people associated with these contexts (e.g., partner, child, sister, mother, etc.).

- Where applicable, the facilitator can list the participants’ responses in categories.

Note: Throughout the meeting, the facilitator should:

- Support the participants along their journey to disclose or not disclose their HIV-positive status.

- Encourage the participants to support each other’s journeys.

- Place no value judgements on participants’ decisions, be it to disclose or not disclose their HIV-positive status.

Continued on the next page...

Life Situations

The facilitator asks the participants about the people to whom they may or may not reveal their HIV positive status:

- “Whom have you told about your HIV-positive status?”
- “Whom have you not told?”
- “Have you felt or do you feel pressured to tell certain people?”

Examples of people who might be told or not told about the participant’s HIV-positive status:

- Immediate family members, distant family members, child/children, partner/spouse, potential partners, co-workers, boss, dentist, nurse, doctor, esthetician...

Examples of such people listed by context:

- **Family Life:**
  - Immediate family members
  - Distant family members
  - Child/children

- **Work Life:**
  - Co-workers
  - Boss
  - Human resources
  - Insurance company

- **Social Life:**
  - Friends
  - Neighbours

- **Love Life:**
  - Sexual partner(s)
  - Partner(s), spouse(s)
  - Potential partner(s)

- **Medical/Hospital Setting:**
  - Dentist
  - Nurse
  - Doctor
  - Esthetician

Life Situations

Should I Tell or Not Tell?

- The purpose of the game is to get the participants to identify the type of obligation (i.e., legal, moral or medical) they may feel when it comes to disclosing their HIV-positive status in various situations.

Instructions

1. The facilitator separates the participants into three groups (two or three participants per group).
2. The facilitator then distributes the “Very Different Obligations” and “Contextual Images” activity sheets to each group. Other images can also be suggested to the participants at the facilitator’s discretion.
3. For each image representing people, groups or institutions (e.g., dentist, doctor, family members, sexual partners, etc.), the groups must determine if it is medically, morally or legally important for them to disclose their HIV-positive status to these people. To this end, the participants are asked to put these people into one of three categories on the “Very Different Obligations” activity sheet. The participants should be allowed to use their own judgement during the exercise.
4. Once the exercise is over, each group is asked to present their work to the other participants.
5. As each group presents their work, the facilitator reproduces the participants’ responses on the game board (or blackboard/flip chart).
6. Finally, the facilitator asks the participants if the resulting board is closer to reality (the facts) or their own impressions.

Continued on the next page...

Life Situations

- The purpose of the game is to get the participants to identify the type of obligation (i.e., legal, moral or medical) they may feel when it comes to disclosing their HIV-positive status in various situations.

Making a Game Board (optional)

- To make a game board, divide a large piece of cardboard into the following three categories:
  1. Medically important
  2. Morally important
  3. Legally important (“Very different obligations” activity sheet).

- Laminate it.

- Print and cut out images representing the various situations and laminate them (“Contextual Images” activity sheet).

- Affix pieces of Velcro on the back of each image and on the game board.

Alternative

- The facilitator presents each image to the participants.

- As a group, the participants discuss which category the image should be added to (e.g., medically, morally or legally important).

- Once the group has come to a consensus, the facilitator puts the image on the game board (or writes what the image is on the blackboard or flip chart).

Continued on the next page...
Life Situations

- This activity allows the facilitator to inform the participants about their rights and responsibilities when it comes to disclosing their HIV-positive status and to answer any questions they may have.
- They should know that no person, group or institution can force people living with HIV to disclose their status. This information is strictly confidential.
- No person living with HIV is legally obligated to disclose their HIV positive status to anyone if that is their decision, with a few exceptions (before having sex that poses a “realistic possibility of HIV transmission,” when obtaining insurance, and during immigration).

Sexual relationships

- The image representing two people having sex should appear in the “legally important” column.
- Under the law, a person living HIV has the legal duty to disclose their status:
  - “before having vaginal or anal sex without a condom (regardless of [their] viral load);
  - and “before having vaginal or anal sex with anything higher than a ‘low’ viral load (even if [they] use a condom).”

Source: Canadian HIV/AIDS Legal Network. (2012). HIV non-disclosure and the criminal law: implications of recent Supreme Court decisions for people living with HIV. Q&A. Available online: www.aidslaw.ca

- The facilitator is strongly advised to consult the Canadian HIV/AIDS Legal Network, COCQ-SIDA, and other HIV/AIDS law websites for the latest information on HIV disclosure and Canadian criminal laws.

Life insurance

- The image representing the life insurance agent should appear in the “legally important” column. This would be true for any type of insurance In terms of personal life insurance or disability insurance, the insurance company will ask you to disclose if you are HIV-positive. It is best to tell the truth or the company could refuse to pay out benefits in the event of death or disability.


Available online: http://www.cocqsida.com/mediatheque/publications/les-memes-droits-que-vous.html

Continued on the next page...

Hospital setting

- The images representing the doctor, nurse and dentist should appear in the “medically important” column. To receive quality care that takes into account your state of health, it is best to disclose your HIV positive status to the health professionals you consult.

Available online: http://www.cocqsida.com/ mediatheque/publications/les-memes-droits-que-vous.html

Variations

- The facilitator can give the participants relevant, up-to-date information on the law and their rights with respect to disclosing their HIV-positive status.

- A lawyer or specialist in this area could also be asked to speak to the participants to educate them and answer their questions. This activity could take place at a subsequent meeting or at a conference evening organized as part of the program.

Life Situations

Very Different Obligations

Medically Important  Morally Important

Legally Important

Life Situations

Contextual Images

Life Situations

Contextual Images

Romantic partners

Romantic partners

Romantic partners

Sexual partners

Sexual partners

School teacher

Dentist

Family doctor

Nurse

Life Situations

Contextual Images

Life Situations
Contextual Images

Life Situations

The People in My Orbit

- Using the “The People in My Orbit” activity sheet 1; Grouping by Individuals and “The People in My Orbit” activity sheet 2; Diagram, the participants are asked to list the people in their orbit with whom the issue of disclosure may come up. You can use the “The People in My Orbit” activity sheet 1; Grouping by Individuals to let individuals list the people in their orbit first and then sort them into the diagram.

Within the various concentric circles, the participants are asked to:

1. Indicate in green, in the upper semicircle, the person(s) (or their first names) who know about their HIV positive status.
2. Indicate in red, in the lower semicircle, the person(s) (or their first names) who don’t know about their HIV positive status or to whom they do not wish to disclose their status.
3. Circle in red, in the upper semicircle, the person(s) (or their first names) who are not handling the situation well.
4. Circle in blue, in the lower semicircle, the person(s) (or their first names) they would like to tell.
5. Using blue asterisks (*) evaluate the extent of the moral obligation they feel to disclose their HIV-positive status for each of the people identified
   - * low moral obligation
   - ** medium moral obligation
   - *** high moral obligation
6. The facilitator asks the participants to put the people in their orbit in the various concentric circles, according to how important they are to them (the closer a person is to the centre, the more important that person is in their life).
   - To illustrate, the facilitator does the activity on the board using the sample version of the “The People in My Orbit” activity sheet 2; Diagram.
   - The facilitator then encourages the participants to do the exercise themselves. To keep the activity simple, the participants need only list one or two people in each circle.
   - Once everyone has completed the exercise, the facilitator leads a group discussion and asks the participants about the people in their orbit.

Life Situations

- Invite the participants to reflect on the “people in their orbit”:
  - “Are you more “red” (secretive) or more “green” (open) when it comes to disclosing your status?”
  - “How much has the issue of disclosure come up in your life?”
  - “Are the people you have told the most important people in your life or people you really trust, or are they more people you aren’t that close to?”
  - “When you have shared your status with people, did it generally go well?”
  - “Are there people who are important to you that you haven’t told?”
  - “Of those you haven’t told, whom would you like to tell?”
  - “Of those you haven’t told, whom would you prefer never to tell?”
  - “What do you think makes these two groups different?”

- The concentric circle exercise is a great way for the participants to visualize all the people who are gravitating around them, as it provides a true picture of the configuration of their social network.

- This exercise also allows them to list the people with whom they have daily interactions. By putting an image of themselves inside this network, it becomes easier to see the extent to which disclosure is an issue within their network. It also allows them to see whether the people they have told are the people who are most important to them and with whom they have good relationships, or the opposite.

- The facilitator asks the participants what they got out of the activity on the people in their orbit and discusses with them the moral obligation they feel to disclose their HIV-positive status:
  - Do you feel morally obligated to disclose your status to certain people (e.g., “I feel like I should tell,” “I feel like I have to tell,” “I feel like it is my duty to tell”)? Why do you feel this obligation? Why would it be/is it important for you to tell certain people? Why do you feel/did you feel that telling certain people was the right thing to do?
  - Conversely, are there people whom you do not feel morally obligated to tell? Or people whom you feel morally obligated not to tell? What can you tell us about your relationship with these people?

Life Situations

The People in My Orbit

Friends

Family

Partner(s)/Lover(s)

Service Providers

Community Members

Professional/Work

The People in My Orbit

Life Situations

DISCLOSE

KEEP SECRET

Green: The person knows and is dealing with it well.
Green with a red circle: The person knows but isn’t dealing with it well.
Red: The person doesn’t know and I don’t want to them to know.
Red with a blue circle: The person doesn’t know and I want them to know, but I don’t know how to tell them or can’t.

* Low moral obligation
** Medium moral obligation
*** High moral obligation
Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”
- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and log-book in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 4: Controlling My Own Destiny

**Required Materials for the Meeting**

- Logbook for each participant
- Participant binder/duo-tang
- Blackboard or flip chart and chalk or pencils
- Coloured pencils, crayons or markers
- A pen for each participant

**Print Outs (1 per participant):**
- “Pros and Cons: Activity Sheet 1; List”
- “Pros and Cons: Activity Sheet 2; Grouping Individuals”
- “Rosa’s Story: Activity Sheet; Disclosure and its Consequences”
- “Prudence’s Story: Activity Sheet; Disclosure and its Consequences”
- “Pros and Cons Scale: Activity Sheet; Scale”
- “My Winning Hand: Activity Sheet 1; Factors Favourable to Disclosure”
- “My Winning Hand: Activity Sheet 2; Factors Unfavourable to Disclosure”
- “My Winning Hand: Activity Sheet 3; Playing Cards”

Pros and Cons

- The objective of the following activities is to shed light on the positive and negative consequences of disclosure of participants’ HIV status to generate helpful strategies. This process can provide space for reflection and inform participants on ways to change or strengthen their approach to the issue.

- The facilitator invites the participants to share personal experiences and identify the pros (positive consequences) and cons (negative consequences) of disclosure.

- *The pros and cons of keeping one’s HIV status private will be discussed at future meetings.

  - “What are the advantages of disclosure?”
  - “What are the disadvantages of disclosure?”

- The facilitator writes the participants’ responses on the board or flip chart and then sorts their answers into different categories.

- To facilitate discussion, the facilitator can write different categories on the board or flip chart (e.g. personal, relationship, family, professional/occupational, socio-economic). For each category, the participants identify the pros and cons of disclosure.

- The facilitator is encouraged to refer to the “Pros and Cons: activity sheet 1; List” and “Pros and Cons: activity sheet 2; Grouping Individuals” for the exercise.

- The facilitator can introduce this exercise by reading “Rosa’s Story: activity sheet; Disclosure and its Consequences” and “Prudence’s Story: activity sheet; Disclosure and its Consequences”

- Referring to the stories of Rosa and Prudence, participants then identify the pros and cons of disclosure.

### Controlling My Own Destiny

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Controlling My Own Destiny

Pros and Cons

Friends

Family

Partner(s)/Lover(s)

Service Providers

Community Members

Professional/Work

Disclosure and its Consequences

Rosa, 42, is from Quebec. She found out that she is HIV-positive 12 years ago. Rosa does not have children. She has been living with her partner for 10 years now. Her partner was the first person to whom Rosa decided to disclose her HIV status apart from her doctor and a nurse at the hospital. Furthermore, she maintains that she quit her job before being fired. To feel useful, Rosa sometimes visits schools to educate students about HIV.

Rosa and her boyfriend had been seeing each other for a few months when she told him about her HIV status. At first, he was a little surprised, but he quickly realized that he was already attached to Rosa, that he did not want to leave her and that they could take steps to protect each other. Their relationship continued with no secrets between them.

The second person to whom Rosa disclosed her status was her oldest brother. Before telling him, she worried that he would tell other people. Her fear proved to be justified when her brother told their three other brothers and their mother without asking for Rosa’s permission. Rosa’s mother did not believe the brother and asked Rosa if it was true. Rosa decided to deny it because her mother was very sick, and Rosa did not want the news to aggravate her mother’s health condition.

Rosa also disclosed her status to a friend because she needed to share her secret with someone other than her partner and family. Rosa trusted that the friend would not tell other people they knew.

Disclosure and its Consequences
Prudence, 32, is originally from Mali. She has known that she is HIV-positive for 3 years. She believes that she contracted the virus while having sex with her first husband, who is now deceased. Prudence has two children, a 7-year-old boy and a 3-year-old girl. Her children are both HIV-negative. Prudence found out about her status when she was pregnant with her daughter. She then married a man who is HIV-negative. When she told him about her status, he accused her of hiding it from him so she could marry him. Shortly afterwards, they separated.

Prudence has not told her daughter about her HIV yet because she believes her daughter is too young and Prudence does not want to traumatize her. However, she told her son that she is sick, without telling him what she has. He is not sure if it is true or not because Prudence seems to be in good health. Sometimes he asks questions; she reassures him that she is taking care of herself and that everything is going well.

Prudence has not disclosed her HIV status to other family members or friends because she worries that they would judge her. She is also afraid that her family would reject her. For now, she avoids the subject and when HIV comes up she does not talk about herself personally. She believes that one day she will tell people but is waiting for the right time.

Prudence has disclosed her HIV-positive status to her dentist, who has been seeing her since she arrived in Canada. The news did not change her relationship with him—she believes that the care she is receiving from him is as good as before.

Prudence has also disclosed her status to one of her friends because it was important for her to know there was someone who would be able to take care of her children if she had any health problems. While not comfortable with the idea of disclosing, she sees that, in this case, it can be very useful.

Pros and Cons Scale

- While referring to their “The People in My Orbit” activity sheets (from Meeting 3), each participant chooses a context in which the issue of disclosing their HIV-positive status has arisen or could arise (disclosing to parent, child, etc…).

- The participants write down the pros and cons of disclosure in this context on the “Pros and Cons Scale” activity sheet. It is suggested that participants include a maximum of three pros and three cons. The participants assess the importance of each pro and con, using a measuring stick to represent the weight of each pro and con in the chosen context.

Instructions:

- Participants choose a situation where they have disclosed or anticipate disclosing and write it at the top of the page (disclosing to parent, child, etc…).

- Participants list a maximum of three pros and three cons for disclosure in that situation, under “Pros” and “Cons” at the bottom of the page.

- Participants choose one colour for their pros and another for their cons (e.g., blue for pros and orange for cons).

- Participants take a few moments to reflect on the importance of each pro and con.

- After reflecting, each participant indicates the importance of each pro and con by marking each measuring stick at the appropriate height, filling in the stick with the colour they have chosen. The higher the colour on the stick, the more important the pro or con is to the participant (i.e., the more weight it has on their scale). The lower the colour is on the stick, the less important the pro or con is to the participant (i.e., the less weight it has on their scale). Each stick is marked from 0 to 10, with 0 being not important at all and 10 being very important.

- Participants weigh the pros against the cons on the scale. If the pros outweigh the cons, participants will conclude that there may be more benefits than drawbacks to disclosing in that context. However, if the cons outweigh the pros, participants conclude that it might be better to not disclose, at least for now.

- The facilitator should also keep themes of physical, emotional, mental, etc. safety in their mind or as something to bring up as an influencer of disclosure to participants.

- The facilitator asks the participants if the pros they identified are heavier on the scale than the cons or if the reverse is true.

## Controlling My Own Destiny

### Pros and Cons Scale

**SITUATION / CONTEXT OF DISCLOSURE:**

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PROS TOTAL: \[\frac{\text{_______}}{30}\]  
CONS TOTAL: \[\frac{\text{_______}}{30}\]

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Controlling My Own Destiny

My Winning Hand

- Ask participants the following question and write their answers on the board or flip chart:
  - “When you think about the word “disclosure,” what words come to mind?”
- The picture of disclosure that emerges may be both positive and negative. Not everyone has the same disclosure experience. Furthermore, some participants may have never disclosed until now. Some are anticipating negative consequences, and others might be thinking there will be positive consequences. The idea is to point out to participants that not all words associated with disclosure are negative and that disclosure is not only a bad experience. Sometimes, it might not go as expected, and there may be a variety of obstacles hindering disclosure, but there are also ways to overcome those obstacles and minimize the negative consequences.
- People might associate the following words and phrases with disclosure:
  - Complicated, difficult
  - Prejudice
  - Fear of being rejected, stigmatized and discriminated against
  - Shame
  - Not knowing how to go about it
  - Lack of self-esteem and self-confidence
  - Relief, release
  - Acceptance
  - Openness, listening and support
  - Understanding
  - Confidentiality
  - Criminalization
  - Burden, etc.
- The facilitator asks participants to reflect on factors that can make disclosure a positive experience and factors that can make it a negative experience. Participants can refer to their own lives (and to Rosa and Prudence’s stories, if applicable).
  - “What can help me to disclose (favourable conditions)?”
  - “What can I do that would help me disclose (assets)?”
  - “What or who could prevent me from disclosing (obstacles)?”
  - “What can I do to overcome those obstacles (strengths)?”
- The facilitator divides a board or flip chart into four sections that correspond to the four questions above and writes the participants’ answers in the appropriate sections.
- The facilitator completes the chart using the items on the next two pages.

Factors Favourable to Disclosure

- Things that could help me disclose my HIV status (favourable conditions):
  - learning to live well with HIV
  - having a good understanding of HIV
  - being comfortable educating and raising the awareness of people about HIV
  - surrounding myself with supportive people
  - feeling ready to disclose
  - trusting the person I am considering telling
  - believing that the person will be understanding and respect confidentiality, etc.

- Things I can do that would help me to disclose (assets):
  - learning to live well with HIV
  - having a good understanding of HIV
  - being comfortable educating and raising the awareness of people about HIV
  - surrounding myself with supportive people
  - feeling ready to disclose
  - trusting the person I am considering telling
  - believing that the person will be understanding and respect confidentiality, etc.

Factors Unfavourable to Disclosure

- What or who could prevent me from disclosing (obstacles):
  - fear of others’ reactions
  - having young children
  - fear of stigma and discrimination
  - fear for my safety
  - family living far away
  - not knowing how to disclose
  - loved ones’ ignorance of the illness, modes of transmission, symptoms, treatments, etc.

- Things I can do to overcome these obstacles (strengths):
  - prepare myself for all types of reactions
  - inform my children about HIV and equip them to cope with stigma
  - understand my rights, stand up for them and ensure that they are respected
  - wait to meet with family members in person
  - talk to healthcare professionals or other people who have already gone through a similar experience
  - arrange to be accompanied by healthcare professionals before or during disclosure
  - educate others and raise awareness about HIV (modes of transmission, symptoms, treatments, etc.)

Controlling My Own Destiny

The facilitator hands out the set of playing cards from the “My Winning Hand” activity sheet to each participant and ask them to spread out their cards.

Participants will select a context from their “The People in My Orbit” activity sheets.

In regards to the context they have chosen from their “The People in My Orbit” activity sheets, the facilitator then asks the participants to write on the corresponding cards:

1. An ideal condition for disclosure,
2. An obstacle to disclosure,
3. A factor that could encourage disclosure, and
4. One of their strengths that could help them to overcome an identified obstacle to disclosure.

Instructions:

After the group brainstorms, the facilitator distributes one card from each suit (hearts, clubs, spades and diamonds) and a pen to each participant (or the page “My Winning Hand” activity sheet).

The facilitator asks the participants to identify, from the answers on the board or flip chart:

- “What is the ideal condition you believe to be most important for facilitating disclosure? Write it on your heart card.”
- “What is your most significant obstacle to disclosure? Write it on your spade card.”
- “What can you can do (your asset) to reinforce the ideal condition (heart card) that facilitates disclosure? Write it on your diamond card.”
- “What can you do (your greatest strength) to overcome the obstacle (spade card)? Write it on your club card.”

The goal of this exercise is to make disclosure scenarios more tangible and allow participants to realize that they possess assets and strengths that could help them overcome obstacles to disclosure. The hand of cards in the exercise is theirs, so they have the opportunity to construct a winning one before disclosure.


Controlling My Own Destiny

My Winning Hand

My greatest strength to help me overcome my obstacle

My obstacle to disclosure

My greatest asset to reinforce disclosure in an ideal location

My ideal condition

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”

- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and log-book in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 5: Sharing to Better Support Eachother

Required Materials for the Meeting

- Logbook for each participant
- Participant binder/duo-tang
- A board or flip chart and chalk or pencils
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons and/or markers
- Coloured poster board to make the cards
- A pen for each participant

Print Outs (1 per participant):

- “The Allegory of the Wise Chameleon: Activity Sheets”
- “Rosa’s Story: Activity Sheet; Disclosing with Rosa and Prudence”
- “Prudence’s Story: Activity Sheet; Disclosing with Rosa and Prudence”
- “My Strategic Plan: Activity Sheet 1; Treasure Map”
- “My Strategic Plan: Activity Sheet 2; Chess Match”
- “My Strategy Card: Activity Sheet”
- “Encouragement Card: Activity Sheet 1; From Within”
- “Encouragement Card: Activity Sheet 2; From Others”

Once upon a time, some people built their village at the foot of a mysterious hill. At the top of the hill there was only a crude hut and a very old apple tree.

That is where a wise chameleon lived. They had descended from several generations of prehistoric reptiles and was recognized for its wise advice. Their favourite place to relax was in the gigantic apple tree overlooking the valley.

Back then, a village custom when people had a problem was to go to the wise chameleon’s hut to ask their advice. They always gave the villagers the same response:

There are four steps to resolving your problem:

- First, you have to turn yourself into a detective that is, you have to observe the situation and note all the important elements of the problem. You have to understand the basis of the problem before you can resolve it.
- Second, you have to act like an architect to analyze the problem. Illustrate it on paper, with some kind of diagram or drawing.
- Third, you have to be like a carpenter, to carry out the plan you produced when you were the architect. You will implement the solution you came up with in steps one and two.
- Fourth, you will turn into a referee to verify all the data for the problem one last time and decide if the solution is suitable. If so, there you go! Otherwise, you will have to start the process over, and then you will certainly find the solution.

Continued on the next page...

The Allegory of the Wise Chameleon

One day, the chief of the village, who had a serious conflict with her son, resolved it by following that wise advice. A village couple, who were having trouble finding the key to the mystery that was ruining their happiness, also followed the chameleon’s recommendations and found happiness and harmony again.

Nearly all the residents of the village had consulted the wise chameleon at some time, and they all came back down the hill with shining faces because they had found their solutions, too.

One day, however, lightning hit the giant apple tree, and the wise chameleon, who was lounging in the tree at the time, perished along with it. What misfortune!

Despite the loss of the wise chameleon, the villagers continued to go to the hut to attempt to resolve their problems and found their solutions by remembering those four steps.

One stormy night, the wise chameleon’s hut fell down, and the people stopped going up there. When they encountered a problem, they only had to glance at the top of the hill to remember how effective the wise chameleon’s four steps were.

That’s how the wise chameleon’s message was handed down from generation to generation. Every time a villager had a problem, they remembered the four steps and put them into action, and they were always successful.


Sharing Knowledge and Experience

- Throughout the meeting, the facilitator should:
  - Support the participants in their process of disclosing or not disclosing.
  - Ask the participants to support each other in their respective processes.
  - Place equal value on both disclosing one’s HIV-positive status and keeping it secret.
- The facilitator introduces the idea that there are four approaches to disclosing one’s HIV status.
  - “Can you name the four approaches to disclosure?”

Four Approaches to Disclosure

1. **Secret disclosure**: This involves disclosure to only a few people from whom complete confidentiality is required—for example, the person’s partner and parent.
2. **Selective disclosure (most common)**: Individuals evaluate the situation before disclosing and open up to those with whom they have quality relationships, who can keep the secret, or who can help them with their health. Other factors may encourage selective disclosure, such as the risk of sexual transmission to a partner.
3. **Complete disclosure (rare)**: Individuals consider it important to disclose their status without taking into consideration the people to whom they are disclosing and do not require complete confidentiality. The individuals disclosing in this way do so for social, political or educational reasons.
4. **Unwanted disclosure**: Although rarely documented, this phenomenon of someone disclosing another person’s status without their consent is real. The breach of confidentiality often comes from family members and healthcare professionals.

Sources:


The facilitator invites the participants to share their disclosure experiences (it is recommended that a person who has had a positive experience and a person who has had a more difficult one be selected).

The facilitator can introduce this exercise by reading “Rosa’s Story: Activity Sheet; Disclosing with Rosa and Prudence” and “Prudence’s Story: Activity Sheet; Disclosing with Rosa and Prudence.” Participants can be asked to identify the disclosure strategies used by Rosa and Prudence.

- “Does anyone want to share a disclosure experience that went well?”
- “Has anyone had a more difficult experience?”

The facilitator can next ask the participants to point out the disclosure strategies used by the participants who shared their experiences or those used by Rosa and Prudence or to describe other disclosure strategies they know of.

**Disclosure Strategy Examples**

- decide on the person to whom you want to disclose
- ask for support from your social worker, the psychosocial team at the hospital or another healthcare professional
- participate in support groups
- read up on the subject
- give yourself time to prepare emotionally
- test the attitude of people close to you about people living with HIV and about HIV
- write a letter
- disclose over the phone
- leave your HIV medications out
- make presentations in schools or to your community to raise people’s awareness about HIV
- disclose individually to each of your family members
- continue relationships only with those who accept you
- get physically active and work on reducing the stress of disclosure
- call a friend to talk about the disclosure experience
- engage in an activity you especially like to get your mind off it
- give the person to whom you disclose time to digest the news
- refer that person to a healthcare professional
- be available to answer questions from the person (know your boundaries)

The facilitator sections off the board or flip chart into three categories:

1. **Preparing to disclose**
2. **Strategies**
3. **After disclosure**

As the facilitator poses questions to the participants, they write down what the participants say in the appropriate category:

- “How can we prepare for disclosure?”
- “What were the disclosure strategies used by those who shared their experience?”
- “What disclosure strategies did Rosa and Prudence use?”
- “Do you know of, or can you imagine, any other disclosure strategies?”

The facilitator fills in the table with items from the participants and text below:

<table>
<thead>
<tr>
<th>Preparing to Disclose</th>
<th>Disclosure Strategies</th>
<th>After Disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decide whom you want to tell in your family</td>
<td>Write a letter</td>
<td>Continue relationships only with those who accept you</td>
</tr>
<tr>
<td>Ask for support from a social worker, hospital psychosocial team, etc.)</td>
<td>Disclose over the telephone</td>
<td>Get physically active and work on relaxation to reduce the stress of disclosing</td>
</tr>
<tr>
<td>Participate in support groups</td>
<td>Leave your HIV medications out</td>
<td>Call a friend</td>
</tr>
<tr>
<td>Test people’s attitudes</td>
<td>Talk about your experience in schools or community to raise awareness</td>
<td>Engage in an activity you especially like to get your mind off it</td>
</tr>
<tr>
<td>Read up on the subject</td>
<td>Disclose individually to each family member, etc.</td>
<td>Give the person to whom you are disclosing time to digest the news</td>
</tr>
<tr>
<td>Give yourself time to prepare emotionally</td>
<td></td>
<td>Refer that person to a healthcare professional</td>
</tr>
</tbody>
</table>

The facilitator then asks the participants how they can prepare for people’s reactions:

- “Have you considered the reaction of the person to whom you would like to disclose?”
- “How are you going to respond/how have you responded to that reaction?”
- “How can you protect yourself emotionally or take care of yourself if it does not go well?”

The facilitator can provide participants with references from several HIV resources in Canada.

Other leaflets and brochures on disclosure may also be given to participants.

Rosa’s Story

Disclosing with Rosa and Prudence
Rosa, 42, is from Quebec. She found out she is HIV-positive 12 years ago. Rosa has no children. She has been living with her partner, to whom she is not married, for 10 years now. Her partner was the first person to whom Rosa decided to disclose her HIV-positive status besides her doctor and a nurse at the hospital. Furthermore, she maintains that she quit her job before being fired. To feel useful, Rosa sometimes gives talks about her status to student audiences.

After being with her partner for 6 months, Rosa felt that their relationship was serious and that she could trust him. She had asked him if he knew anything about HIV and whether he knew people who had it, to test his attitude toward HIV and people living with the disease. Because he had seemed very open, she felt comfortable enough to tell him her secret. Rosa decided to do it over the telephone, because she thought that distance would allow her to be less emotional and allow her to explain everything she planned to say.

Later, Rosa decided to disclose her HIV status to her oldest brother. Because they were very close, she felt obligated to tell him. Unfortunately, her brother did not keep the secret with which Rosa had entrusted him and told their 3 other brothers and their mother without asking Rosa’s permission.

Continued on the next page...
Disclosing with Rosa and Prudence
Then Rosa met with all of her brothers so she could tell them herself. She told herself that, in some way, her oldest brother had broken the ice and that it was all for the best. After the experience with that brother, Rosa also realized that it might be very difficult for her other brothers to keep a secret like that. So, when she spoke to them, she put a lot of emphasis on the fact that she trusted them and needed them to be discreet. Although things went faster than she thought they would, she reacted calmly by reflecting on the positive aspects of the situation.

Now Rosa can talk about her health with all four of her brothers without fearing that her secret will be discovered.

Rosa also decided to disclose her status to her closest friend. One evening when they were alone at her place, chatting about anything and everything, Rosa decided to put a leaflet on antiretroviral treatments on the living room table. She thought that her friend would bring up the subject or ask her why she was reading that type of thing and then it would be easier for Rosa to talk about it. She was hesitant about using the leaflet because she could also bring up the subject by relating it to a movie or the news. Recently, she had the idea of disclosing her status to another friend by inviting her to join her in a walk for the Farha Foundation, which raises money every year for people living with HIV.
Disclosing with Rosa and Prudence
Prudence, 32, is originally from Mali. She has known that she is HIV-positive for 3 years. She believes that she contracted the virus while having sex with her first husband, who is now deceased.

Prudence has two children, a 7-year-old boy and a 3-year-old girl. Her children are both HIV-negative. Prudence found out about her status when she was pregnant with her daughter. She then married a man who is HIV-negative. When she told him about her status, he accused her of hiding it from him so she could marry him. Shortly afterwards, they separated.

Prudence felt that the time had come to talk to her kids about her HIV status. She felt ready and well-prepared, but she decided to take her children to meet with her social worker so someone else could explain things to them. She believed that her children had the right to know what was going on but that it was important to choose the right time. To prepare herself, she thought about the questions and concerns her children might have by putting herself in their position. She thought, “What if my mother had revealed such a secret to me when I was only seven!”

Prudence also had to manage the question of disclosure with a friend with whom she lived after her separation. This friend had asked a lot of questions about Prudence’s medications, but, at that time, Prudence was pregnant and told her they were for her pregnancy. However, after having her baby, she continued to take the same medications. Prudence found the situation awkward and was tired of always having to hide what was going on. At first, Prudence thought about getting a babysitter for the children and the two of them having a girls’ night out. She told herself that by choosing the right time and place and by thinking through how she would tell her friend, she would feel more in control of the situation. However, when it came down to it, the idea of the disclosure made Prudence too anxious, so she decided to tell her about her HIV in a long letter in which she explained how her friendship was important to her and that she regretted having to hide the truth from her for so long.

Continued on the next page...

Disclosing with Rosa and Prudence
Prudence did not disclose her status to her family members, some of whom are living in Quebec, because she is afraid that some of them would reveal it to people in her community. She does not want her children or her to be the subject of rumours or finger-pointing. She also knows that there is lots her family does not know about HIV and she has heard them express prejudiced views towards people living with HIV. For now, she has decided to not disclose to her family, but to discuss the subject in a less personal way. Sometimes, she comments on a report or an article about HIV and tries to raise their awareness. This way, when she is ready to disclose, it will be less difficult. She is waiting to be ready herself but also for her family members to be ready.

With time, she is gradually warming up to the idea of disclosing to her mother, who lives in Mali. Prudence would like to be able to talk to her about her concerns regarding her status and her children. She believes that her mother can support her despite the many kilometres between them. However, she vacillates between the possibility of returning to Africa before telling her and telling her over the phone. Her next trip might not be for several years, but she believes that her mother would understand better if Prudence could tell her in person. So Prudence will only tell her over the phone if it is an emergency.
My Strategic Plan

- The facilitator and the group read the “My Strategic Plan” activity sheet.
- Afterwards, the facilitator asks each participant to complete their strategic plan. Participants complete “My Strategic Plan: activity sheet 1; Treasure Map” for an anticipated disclosure and “My Strategic Plan: activity Sheet 2; Chess Match” for a previous disclosure.
- The participants are asked to answer the following questions while completing “their strategic plan.”
- This exercise may also be done in pairs of one participant who has already disclosed their HIV status and one participant who has not disclosed in the same context.
- The facilitator can give each participant the “My Strategy Card” activity sheet to fill out after the other participants have described the strategies they used in question 13 and 15. The goal of this exercise is to help each participant think about strategies that could be used in other contexts.

Disclosure Context

Anticipated Disclosure; Treasure Map

1. To whom am I going to disclose my HIV status? Choose the person and determine whether or not that person’s characteristics are influencing your decision to disclose—for example, their gender, age, health condition.
2. Why do you want to disclose? Clarify your intended objective of and motivation for disclosing.
3. When do you want to do it? What is the best time?
4. Where do you want to do it? What is the best place?

Previous Disclosure; Chess Match

1. To whom did you disclose? Why did you choose to disclose to this person?
2. Why did you decide to disclose your HIV status? What was your objective and motivation for disclosing?
3. When did you think the best time for disclosing was?
4. Where did you think the best place for disclosing was?

Decision/Support/Certainty

**Anticipated Disclosure; Treasure Map**

5. Where are you in terms of your decision to disclose? (e.g., I have not thought about it yet, I am thinking about it, or I have almost decided)
6. Are you feeling pressure from others to disclose?
7. Are you getting enough support from others in making the decision?
8. Are you sure it’s the best choice for you?

**Previous Disclosure; Chess Match**

5. What were you thinking at the moment you disclosed?
6. Did you get support from others beforehand?
7. Did you decide to disclose under pressure from others?
8. Were you sure it was the best choice for you?

Skills/Knowledge

**Anticipated Disclosure; Treasure Map**

9. Do you feel equipped to answer questions about your health?
10. Are you prepared and do you have enough information to disclose?
11. What question(s) do you anticipate from the person you want to tell?
12. What is your plan if disclosure does not go well?

**Previous Disclosure; Chess Match**

9. Did you feel informed enough to disclose?
10. What question(s) did you anticipate from the person you told?
11. Did you feel you were equipped to answer questions about your health?
12. Did you have a plan in case the disclosure did not go well?

Strategies/Experience

Anticipated Disclosure; Treasure Map
13. What disclosure strategies do you intend to use?
14. How do you use this strategy to assess the feasibility of disclosing in this particular context?
15. Have you disclosed your HIV status to others? If so, what strategies did you use? Would those strategies be useful in this context?

Previous Disclosure; Chess Match
13. What disclosure strategies did you use?
14. How did you use this strategy to assess the feasibility of disclosing or not disclosing in this particular context?
15. Have you disclosed your HIV status to others? If so, what strategies did you use? Would those strategies be useful for this exercise?

- The facilitator invites the participants to share their answers to questions 13 and 15 (or their “My Strategy Card” activity sheet) of their strategic plan with the group.
- In closing, the facilitator reviews the exercise with participants:
  - “After completing your strategic plan, are you thinking about disclosure differently?”
  - “Considering your “winning hand” (from Meeting 4) and your strategic plan for an anticipated disclosure, when do you think you will be ready to disclose?”
  - “Considering an experience you may have already had disclosing, how do you think it went?”

**My Strategic Plan; Should I Disclose?: Treasure Map**

1. **The Situation**
   - To whom am I considering disclosing?
   - Is there anything about this person I could consider prior to disclosing?
   - Why?
   - When?
   - Where?

2. **The Decision**
   - Am I making this decision because of pressure from others?
     - Yes
     - No
   - How much have I thought about this decision?
     - No decision
     - Reflection underway
     - Almost ready to know where I stand
     - My decision is made
   - Am I supported in this decision?
     - Yes
     - No
   - Am I certain that this is the best choice for me?
     - Yes
     - No
   - How (What are my strategies)?
     - On a scale of 0—5, how attainable/realistic are your strategies?

3. **Support/Certainty**
   - Do I feel like I have adequate tools to deal with questions about HIV and/or my health?
     - Yes
     - No
   - Do I have other disclosure strategies? Could past strategies be useful in this situation?
     - Yes
     - No
   - What is my plan if my disclosure does not go well or the person has a negative reaction?
     - Yes
     - No

My Strategic Plan; For Past Disclosures: Chess Match


My Strategy Card

**Encouragement Card**

- The facilitator hands out *“Encouragement Card: Activity Sheet 1; From Within”* to participants. Participants will write encouraging messages/words, positive qualities, or a strength they see in themselves that may help them with HIV disclosure or for overcoming obstacles.

- To encourage participants to support each other in the delicate process of planning to tell people about their HIV status, the facilitator invites them to make cards with encouraging messages for each other.

- Each participant receives a *“Encouragement Card: Activity Sheet 2; From Others,”* writes their name at the top, and then passes it to each person at the table. The other participants should write encouraging messages/words, positive qualities, or a strength they see in that individual that may help them with HIV disclosure or for overcoming obstacles. The cards are handed back to their owner indicated by the name at the top of the card.

- Those who wish, can respond to the cards they receive.

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Encouragement; From Others

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”
- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and logbook in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 6: Secrets to Keeping Your Secret

Required Materials for the Meeting

- A logbook for each participant
- Participant binder/duo-tang
- A blackboard or flip chart and chalk or markers
- A pen for each participant
- Monopoly money in all denominations ($30 for each participant)
- A box containing feathers OR a ball

Print Outs (1 per participant):
- “Rosa’s Story: Activity Sheet; Secrets and their Consequences”
- “Prudence’s Story: Activity Sheet; Secrets and their Consequences”
- “My Savings Account: Activity Sheet”
- “My Secret Code: Activity Sheets”

Secrets to Keeping Your Secret

Pros and Cons

- The objective of this meeting is to assess the possible consequences of keeping one’s secret in various contexts.

- Throughout the meeting, the facilitator should:
  - Support the participants along their journey to disclose or not disclose their HIV-positive status.
  - Encourage the participants to support each other’s journeys.
  - Place no value judgements on participants’ decisions, be it to disclose or not.

- Before having the participants list the “pros” and “cons” of keeping their secret, the facilitator can introduce this exercise by reading “Rosa’s Story: Activity Sheet; Secrets and their Consequences” and “Prudence’s Story: Activity Sheet; Secrets and their Consequences” for inspiration.

Brainstorming session:

- From their personal history, the participants determine the “pros” (positive consequences) and “cons” (negative consequences) of keeping their status a secret.

- The “pros” and “cons” of keeping their status a secret will have been discussed in previous meetings.
  - “Can you list some advantages of keeping your status a secret?”
  - “Can you list some disadvantages of keeping your status a secret?”

- To facilitate this exercise, write different categories on the board (e.g. work life, family life, etc.). For each, participants can list the pros and cons of keeping their status a secret.

- The facilitator writes the participants’ responses on the board. Refer to the next facilitator’s page for further information and examples.

Secrets and their Consequences
Rosa, a 42-year-old woman born in Quebec, has known that she is HIV-positive for 12 years. Rosa has no kids and has lived with her common-law spouse for 10 years. They aren’t married. He was the first person she told about her HIV status, after her doctor and a nurse at the hospital. She maintains that she quit her job before being fired. To feel useful, Rosa sometimes speaks at schools.

When Rosa’s brother told their mother, she didn’t believe him and asked Rosa if it was true that she had HIV. Rosa denied it because her mother was very ill and she didn’t want the news to make her condition worse. In this situation, Rosa truly believed that not telling her mother was the right decision, even though there are times when she wishes she could lean on her mother for support. Still, she knows that there are other people in her life who are there for her and that maybe, someday, if her mother’s health improves, she can have a long talk with her.

Rosa generally finds it easy to keep her HIV-positive status a secret. However, she admits that it can be difficult at times, like when she has to make excuses with certain people to explain her frequent visits to the hospital. This makes her feel like she isn’t being authentic—like a part of her is hiding, living in the shadows, unable to express itself. On the other hand, she feels that this is personal information and that she is hardly the only one with secrets. What bothers her is why she should even have to hide her condition. It’s not like she has anything to be ashamed about…but she knows that not everyone is as open and understanding as her husband and friend.

Prudence’s Story

Secrets and their Consequences
Prudence, a 32-year-old woman originally from Africa, has known that she is HIV-positive for 3 years. She thinks she became infected through sex with her first husband, who has since passed away. Prudence has two children, a 7-year-old son and a 3-year-old daughter. Both kids are HIV-negative. Prudence knew she was HIV-positive when she was pregnant with her daughter. She had remarried, to a man who didn’t have the virus. When he found out she was HIV positive, he accused her of hiding her status so she could marry him. They separated and no longer live together.

Prudence hasn’t told anyone in her family and hardly any of her friends about her status, fearing they will reject her, so she just avoids the subject. Maybe she will tell them the truth someday but not until people with HIV aren’t so discriminated against. For now, she finds the secret a heavy burden to bear. She sometimes feels isolated despite having joined HIV support groups and attending a few meetings. The problem is, every time she goes to one, she fears that people from the community will recognize her and tell people in her family, some of whom still live in Africa. It would be awful if her mother found out from someone other than her. Basically, Prudence feels like if she reveals her status, she won’t be embraced and encouraged, so why bother?

Prudence also has a part-time job, and her boss has no idea that she is HIV-positive. She believes that there’s no point in him knowing since her condition hasn’t affected her job performance. Plus, if she tells him, he might judge her and she could lose her job. Besides, this is personal information and it’s not like they’re close. One of her co-workers has seen a therapist for years and she has never told their boss. The only thing that worries Prudence is her insurance. She hopes her boss doesn’t have access to her medical records.

Brainstorming Session

- The “pros” of keeping my secret (here is a possible list):
  - to keep my kids from being stigmatized and socially discriminated against, to avoid rejection, to safeguard the health of a loved one, to keep my job, to avoid being stigmatized and socially discriminated against, etc.

Example of where these pros can fit into different categories:

<table>
<thead>
<tr>
<th>Work-related</th>
<th>Family-related</th>
<th>Relationship-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>keeping my job</td>
<td>to avoid rejection</td>
<td>to safeguard the health of a loved one</td>
</tr>
<tr>
<td>to avoid being stigmatized and socially discriminated against</td>
<td>to keep my kids from being stigmatized and socially discriminated against</td>
<td></td>
</tr>
</tbody>
</table>

- The “cons” of keeping my secret (here is a possible list):
  - feeling isolated, the fear of being “outed” by others, the burden of keeping my secret, always having to hide or lie about my health, having to lead a double life, etc.

Example of where these cons can fit into different categories:

<table>
<thead>
<tr>
<th>Work-related</th>
<th>Family-related</th>
<th>Relationship-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>always having to hide</td>
<td>the fear of being “outed” by others</td>
<td>feeling isolated</td>
</tr>
<tr>
<td>being discriminated</td>
<td>the fear of being rejected</td>
<td>the burden of keeping my secret</td>
</tr>
<tr>
<td>against having to lie about my health, etc.</td>
<td>the burden of keeping my secret</td>
<td>always having to hide</td>
</tr>
<tr>
<td></td>
<td>always having to hide</td>
<td>rejection/separation</td>
</tr>
<tr>
<td></td>
<td>having to lie about my health, etc.</td>
<td>always having to hide</td>
</tr>
<tr>
<td></td>
<td></td>
<td>damaging my relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>having to lie about my health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>leading a double life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>potential criminal prosecution, etc.</td>
</tr>
</tbody>
</table>

My Savings Account

- Using their “The People in My Orbit” activity sheets (see Meeting 3), each participant should choose a scenario in which the issue of keeping their HIV-positive status a secret can come up (a past or anticipated situation).

- For the scenario they have chosen, the participants should list the “pros” and “cons” of keeping their secret on the “My Savings Account” activity sheet (a maximum of three “pros and “cons” is suggested).

- On a scale of 0 to 10, the participants should determine what each “pro” contributes to their well-being and what each “con” costs them in terms of energy.

- The idea is for them to add up their deposits (benefits) and withdrawals (energy spent) when it comes to keeping their secret in a given context, or in other words, to determine whether it is worth it to keep the secret in that context.

- Organizing one’s thoughts by theme and putting them on paper can promote critical thinking and inspire people to make positive changes.

- The goal is to shed light on the positive and negative consequences for the participants of keeping their HIV-positive status a secret and to create strategies that will benefit them. This process can help the participants reflect and may shed light on changes they need to make or factors they need to consider.

Continued on the next page...
• Complete the “My Savings Account” activity sheet using the information below:

Instructions:
• The participants should choose a non-disclosure scenario and write it in the designated space (step 1).

PROS
• The participants write three PROS related to the non-disclosure scenario (step 2).
• In the DEPOSITS column, they assign a number from 0 to 10 to each PRO. This number allows them to quantify the benefits of keeping their secret (step 3).
• The participants add up all these numbers to obtain their TOTAL PROS score (step 4).
• On the basis of this score (0 to 30), the facilitator (banker) then gives each participant the equivalent amount of Monopoly money.

CONS
• The participants write three CONS related to the non-disclosure scenario (step 5).
• In the WITHDRAWALS column, they assign a number from 0 to 10 to each CON. This number allows them to quantify the amount of energy it takes to keep their secret (step 6).
• The participants add up all these numbers to obtain their TOTAL CONS score (step 7).

Continued on the next page...
Instructions:

**BALANCE**
- The participants calculate their grand total by performing the following calculation:
  - TOTAL PRO SCORE − TOTAL CON SCORE = GRAND TOTAL (the result can be positive (x) or negative (-x) (step 8).
- If the GRAND TOTAL is positive (x), then keeping their secret benefits them more than it costs them in terms of energy. So for now, it’s better for them to keep their secret.
- If the GRAND TOTAL is negative (-x), then keeping their secret costs them more in terms of energy than it benefits them. So it may be better for them to reveal their secret.
- On the basis of the score obtained (0 to 30), each participant should give back the equivalent cash amount to the facilitator (banker). If the total is more than what the participant has in the bank, then they give the banker all of their money.
- To end this exercise, the facilitator (banker) asks the participants if they saved money ($) or spent more than they had in their savings account.
  - “*Do your results validate your decision to keep your secret?*”

## Secrets to Keeping Your Secret

### My Savings Account

<table>
<thead>
<tr>
<th>Scenario</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>Indicate the non-disclosure scenario you have chosen</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>PROS</th>
<th>DEPOSITS (in terms of well-being; rank from 0—10)</th>
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</table>

**TOTAL PROS**

<table>
<thead>
<tr>
<th>CONS</th>
<th>WITHDRAWALS (in terms of energy; rank from 0—10)</th>
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</thead>
<tbody>
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</table>

**TOTAL CONS**

**GRAND TOTAL** *(Total PROS - Total CONS)*

Secrets to Keeping Your Secret

My Secret Code

- The picture painted by this activity can be both positive and negative. Not everyone has the same experience when it comes to their secret. Some participants in the group may have decided to never keep their HIV-positive status a secret. Some may see negative consequences in doing so, while others may see positive consequences. The idea is to make the participants see that keeping their status a secret may be necessary in some situations and may not be a bad thing in other situations. It can be difficult to tell in some situations, leading participants not to disclose, even though they may want to. It can also be difficult for participants not to tell, even when this is their choice. It could be that various obstacles are making it difficult for them to disclose, although there are ways to minimize the negative consequences of disclosing and to overcome these obstacles.

- The facilitator asks the participants what the word “secret” means to them and writes their answers on the board.
  - “When you think of the word “secret” what words come to mind?”

- The facilitator then asks the participants to think of situations where it is best for them to keep their HIV-positive status a secret. Next, the facilitator asks them to think of obstacles that might prevent them from keeping their secret. The participants can use their own situation and/or experiences (or use short stories, if applicable).

- The facilitator divides the board into five categories and writes the participants’ answers to the above questions in the appropriate category (see next page for examples).
  - “In what situations or contexts is it best for you to keep your HIV-positive status a secret?”
  - “In these situations or contexts, what do you do to keep your status a secret (ideal conditions)?”
  - “What could you do that would make it easier for you to keep your status a secret (assets)?”
  - “What might prevent you or what does prevent you from keeping your status a secret (obstacles)?”
  - “What has helped you overcome obstacles that you encountered in trying to keep your status a secret? What could help you?”

Secrets to Keeping Your Secret

The facilitator completes the board using the content details in the box below:

**SITUATIONS WHERE IT MAY BE BEST TO KEEP THE SECRET**
- during a job interview
- at work
- when my kids are young
- when my safety may be compromised

**WINNING CONDITIONS (which favour keeping the secret)**
- hiding my medications
- lying about the types of medications I am taking
- having people in my life who respect my desire not to talk about it
- not telling my young kids to make sure they don’t reveal my status
- following my treatment as prescribed
- keeping certain people at a distance, etc.

**ASSETS**
- controlling my reactions to people’s discriminatory comments or attitudes about people living with HIV
- knowing my rights not talking about the side effects of my treatment staying active to avoid suspicion, etc.

**OBSTACLES (which do not favour keeping the secret)**
- rumours or doubts about me
- being “outed” by someone close to me
- broken confidentiality by a health professional
- disease, hospitalization
- taking my medications
- lipodystrophy/lipoatrophy
- not breastfeeding, early weaning of my baby
- situations where there is a realistic possibility of sexual transmission (where the person is legally required to disclose their status under threat of criminal prosecution)
- the fear and stress of being discovered
- feeling like I have to tell
- not being able to work as I did before because of my health, etc.

**STRENGTHS**
- inventing another disease
- ignoring the rumours and doubts being spread about me
- demanding that people stop spreading gossip about my status or face action from the human rights commission
- taking my medication in private
- feeling ok about keeping my secret, etc.

The facilitator distributes the “My Secret Code” activity sheets and asks the participants to complete it, indicating the numbers corresponding to the ideal conditions, assets, obstacles and strengths in the appropriate fields.

The facilitator tells the participants that they can refer to the factors favouring and not favouring keeping their secret indicated on the activity sheet and add others afterwards, taking care to assign a number to them.

The participant should write their non-disclosure scenario on the line below.

For each factor that favours and does not favour keeping their secret, the participant should select a winning condition, an asset, an obstacle and a strength. The participant then writes the number corresponding to each of these in the designated space to create their secret code.

**SITUATION / CONTEXT OF NON-DISCLOSURE:**

<table>
<thead>
<tr>
<th>WINNING CONDITIONS (conditions that favour keeping the secret)</th>
<th>ASSETS (things that can make it easier to keep the secret)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hiding my medications</td>
<td>1. Controlling my reactions to people’s discriminatory comments or attitudes about HIV or people with HIV</td>
</tr>
<tr>
<td>2. Lying about the types of medications I take</td>
<td>2. Knowing my rights</td>
</tr>
<tr>
<td>3. Having people in my life who respect my desire not to talk about it</td>
<td>3. Not talking about the side effects of my treatment</td>
</tr>
<tr>
<td>4. Not telling my young kids to make sure they don’t reveal my status</td>
<td>4. Staying active to avoid suspicion, etc.</td>
</tr>
<tr>
<td>5. Following my treatment as prescribed</td>
<td>5. ...</td>
</tr>
<tr>
<td>6. Keeping certain people at a distance, etc.</td>
<td>6. ...</td>
</tr>
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<td>7. ...</td>
<td></td>
</tr>
<tr>
<td>8. ...</td>
<td></td>
</tr>
</tbody>
</table>

Continued on the next page...
SITUATION / CONTEXT OF NON-DISCLOSURE:

OBSTACLES (things that do not favour keeping the secret)
1. Rumours or doubts about me
2. Being “outed” by someone close to me
3. Broken confidentiality by a health professional
4. Disease, hospitalization
5. Taking medication
6. Lipodystrophy or lipoatrophy
7. Not breastfeeding, early weaning of my baby
8. Situations where there is a realistic possibility of sexual transmission (where the person has a legal duty to disclose their status under threat of criminal prosecution)
9. Situations where there is a possibility of transmission through blood
10. The fear and stress of being discovered
11. Feeling like I have to tell
12. No longer being able to work as I did before because of my health, etc.
13. ...
14. ...

STRENGTHS (things that can be done to overcome the obstacles preventing you from keeping your secret)
1. Inventing another disease
2. Denying the rumours and doubts being spread about me
3. Ignoring the rumours and doubts being spread about me
4. Demanding that people stop spreading gossip about my status or face action from the human rights commission
5. Hiding when I take my medication
6. Telling people I have to take antibiotics if anyone sees me taking my medication and questions me
7. Feeling ok about keeping my secret, etc.
8. ...
9. ...

Secrets to Keeping Your Secret

My Box of Secrets

- This activity is done with a small box filled with a dozen medium-sized feathers.
- This activity can also be done with a ball. Instead of asking a participant to cause the feathers to scatter, the facilitator asks a participant to throw a ball to another participant. In this case, the ball represents the secret. Tossing the ball represents how secrets travel.
- The facilitator explains to the participants that the box represents the secret of their HIV-positive status. To illustrate, the facilitator asks a participant to take their “My box of secrets,” give it to another participant and ask them not to open it.
- The facilitator explains that this gesture symbolizes the participant sharing their secret with another person and asking them to keep it.
- The facilitator then asks the participant with the “My box of secrets” to open it and flip it over so that the feathers fly all over the place.
- The facilitator explains that this gesture symbolizes that the person did not respect the participant’s request to keep their secret.
- The facilitator then asks the other participants to pick up the feathers that fell to the ground.
- The facilitator asks the participants their interpretation of this exercise:
  - “What did this exercise say about the challenges involved in keeping your HIV-positive status a secret?”
- The facilitator adds to the participants’ feedback using the information presented through the bold text below:
  - No matter how strong your “secret code” may be, choosing to share your secret with someone could lead to others finding out; whether you want this or not. Understand that even if you take every precaution to keep your status a secret, others could find out. It’s therefore important for you to be careful with whom they tell; to think about the person’s ability to keep your secret, to determine if this information may be too big a burden for them, to listen and support the person or to refer them to other contacts or resources, if necessary. Understand that once you share your secret, it is more difficult to control and can be a heavy burden for some people to bear.

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”

- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and log-book in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 7: One, Two, Three, HUSH!

Required Materials for the Meeting

- A logbook for each participant
- Participant binder/duo-tang
- A blackboard or flip chart, plus chalk or markers
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons or markers
- A pen for each participant

Print Outs (1 per participant):
- “Rosa’s Story: Activity Sheet; Sometimes Rosa and Prudence Don’t Tell”
- “Prudence’s Story: Activity Sheet; Sometimes Rosa and Prudence Don’t Tell”
- “My Secret Recipe: Activity Sheet”
- “Strategy Card: Activity Sheet”

Let’s Share Our Secrets

- The facilitator encourages the participants to share a past or present experience related to keeping their secret (it would be best to include a person who is having or has had a positive experience and one who is having or has had a more difficult experience).

- The facilitator can introduce this exercise by reading “Rosa’s Story: Activity Sheet; Sometimes Rosa and Prudence Don’t Tell” and “Prudence’s Story: Activity Sheet; Sometimes Rosa and Prudence Don’t Tell” and can then ask the participants to list the “pros” and “cons” for Rosa and Prudence of keeping their secrets.
  - “Can you tell us about the downsides of keeping your secret?”
  - “Is there someone who would like to share a positive experience related to keeping their secret?”
  - “Is there someone who would like to share a negative experience related to keeping their secret?”

- The facilitator asks the participants to share some of the strategies they have used to keep their secret (or to discuss the strategies used in the stories of Rosa and Prudence, where applicable) as well as other strategies they have heard about.

- The facilitator divides the board into three categories:
  1. Managing the secret of your HIV status
  2. Managing the issue of your medications
  3. How to react after you have been “outed”

**Rosa’s Story**

**Sometimes Rosa and Prudence Don’t Tell**
Rosa, a 42-year-old woman born in Quebec, has known that she is HIV-positive for 12 years. Rosa has no kids and has lived with her common-law spouse for 10 years. They aren’t married. He was the first person she told about her HIV status, after her doctor and a nurse at the hospital. She maintains that she quit her job before being fired. To feel useful, Rosa sometimes speaks at school.

Although Rosa’s common-law spouse was the first person she told about being HIV-positive, it took 6 months for her to share the news with him. At first, she told him that she had tuberculosis and had to take medication because her immune system was weak. During that time, she would find any excuse to avoid having sex with him. Since she didn’t want to tell her mother either, she was relieved to hear that her mother didn’t believe her brother when he told her that Rosa was HIV-positive. From that point on, she became very careful around family and friends and stuck to the code of conduct she created for herself. For example, she takes her medications in private and is careful never to leave pamphlets on HIV lying around. Whenever her mother visits, she inspects her home first. And she feels free to call upon her brothers to help her deal with trickier situations.

Prudence’s Story

Sometimes Rosa and Prudence Don’t Tell
Prudence, a 32-year-old woman originally from Africa, has known that she is HIV-positive for 3 years. She thinks she became HIV-positive through sex with her first husband, who has since passed away. Prudence has two children, a 7-year-old son and a 3-year-old daughter. Both kids are HIV-negative. Prudence knew she was HIV-positive when she was pregnant with her daughter. She had remarried, to a man who didn’t have the virus. When he found out she was HIV-positive, he accused her of hiding her status so she could marry him. They are now separated and no longer live together.

Prudence hasn’t told her family that she is HIV-positive. She prefers to not talk about the subject except in general terms and even then she checks herself, taking care not to react too personally. On the other hand, she sometimes talks about having a “friend” with the disease to gauge her family’s reactions. It’s sort of her way of talking about it without revealing that she has HIV herself. Recently, she bumped into someone from her community while at an appointment at the hospital and the person asked her what she was doing there. She said she was visiting a friend, which was sort of true because one of the nurses has almost become a friend after all the time she has spent there. These situations always make her uncomfortable, but fortunately she’s quick on her feet and has lines prepared in case she bumps into someone she knows Prudence also has a few tricks she uses when she calls her mother. For example, when she feels the need to talk about her health, she talks about her symptoms in a more general way because HIV symptoms can mirror those of other conditions and talking about her health in this way allows her to be comforted by her mother.

One, Two, Three, HUSH!

- The facilitator asks the participants the following questions and writes their responses in the appropriate category.
- The facilitator completes the board referencing the text at the bottom of this page.
  - “What are the secret-keeping strategies used by the participants who shared their experiences?”
  - “Do you know of or intend to use other secret-keeping strategies?”
- The facilitator asks the participants about the ways in which they can prepare themselves for being “outed” and writes their responses in the appropriate category.
- The facilitator completes the board referencing the text at the bottom of this page.
  - “How can you prepare yourself for being “outed”?”
  - “What is the best way to react if someone reveals your status without your consent?”
- Example of strategies grouped into three categories:

  **Managing the secret of your HIV status**
  - Looking into people’s attitudes about HIV and people living with HIV
  - Asking a social worker, the hospital’s psychosocial team or a health professional for guidance on your decision
  - Telling white lies
  - Talking to someone you trust about your secret, etc.

  **Managing the issue of your medications**
  - Hiding your medications
  - Taking your medications in private
  - Saying you have another disease, etc.

  **How to react after being “outed”**
  - Filing a complaint with the human rights commission
  - Contacting HIV advocacy and defense groups
  - Asking the person to respect the confidentiality of your medical status
  - Reacting calmly and coolly
  - Not fearing the worst
  - Getting support
  - Speaking to those concerned
  - Denying it, etc.

My Secret Recipe

- The facilitator reads the “My Secret Recipe” activity sheets to the group and then asks the participants to create their secret recipe individually.

- This exercise can also be done in groups of two. Ideally, a participant who is keeping their status a secret in one context should be paired with another participant who is keeping their status a secret in the same situation.

- The participants are asked to answer the following questions:

  1. “With whom and in what situations do you feel it is best to keep your secret? (Identify the specific person(s) or scenario(s)).”
  2. “Why do you prefer not telling these people or not disclosing in these situations? (Specify your reasons and motivations for not telling).”
  3. “Do you intend to tell these people or disclose in these situations at some point? (If so, indicate when and where you might do this).”
  4. “Are you sure that this is the best decision for you?”
  5. “What, if any, of these people’s personal characteristics influenced your decision to not tell them? (Determine the characteristics that influenced your decision to not tell them).”
  6. “Do you feel equipped to deal with people’s suspicions that you are HIV-positive?”
  7. “How would you react to being “outed”?”
  8. “Has anyone ever pressured you to make this decision?”
  9. “How will you go about keeping your secret? (What strategies do you plan to use to keep your secret?)”
  10. “To what extent do you think it is possible for you to keep these people from finding out about your status if you use these strategies?”
  11. “Does keeping your secret affect you in your daily life?”
  12. “How do you cope with your secret? How do you minimize its effects on you in your daily life?”

- The facilitator then invites the participants to share their answers from questions 9—12.

Finally, the facilitator reviews the exercise with the participants.

- “What ingredients do you have in your recipe? What ingredients are you missing? Do you think you could add other ingredients to your recipe?”
- “Now that you’ve created your secret recipe, do you see things differently when it comes to keeping your secret?”
- “Now that you have a secret code (see Meeting 6) and a secret recipe, to what extent do you feel equipped and comfortable keeping your HIV-positive status a secret?”
- Individuals can finish off by writing strategies on their “My Strategy Card” activity sheet.

One, Two, Three, HUSH!

My Secret Recipe

- Here are the main ingredients needed to make your secret recipe a success!
- Create your recipe by indicating the amount of each ingredient you have on hand and other ingredients that you could get later.
- NOTE: Answer the questions on the following pages before making a list of the ingredients you have.
- Feel free to be creative and to add other ingredients to make YOUR recipe unique!

I made the decision to not reveal my HIV-positive status in this situation:
_______________________________________________________________________
_______________________________________________________________________.

- NOTE: The amount on hand can be determined using scaling (0-10)… 0 meaning ‘none’ and 10 meaning ‘all I need.’

<table>
<thead>
<tr>
<th>INGREDIENTS:</th>
<th>AMOUNT ON HAND:</th>
<th>BUY LATER:</th>
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<tbody>
<tr>
<td>Motivation</td>
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<td>Certainty</td>
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<td>Knowledge</td>
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<td>Support</td>
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<td>Strategies</td>
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Continued on the next page...

Motivation
What makes you not want to tell these people you are a person living with HIV?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Do you intend to tell these people at some point?

□ Yes  □ No

If ‘Yes,’ when and where do you intend to tell these people?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Certainty
What makes this the right decision for you?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Are you sure this is the right decision for you?

□ Yes  □ No

Continued on the next page...

Knowledge
What, if any, of these people’s personal characteristics influenced your decision to not tell them?

☐ Age  ☐ Health status  ☐ Proximity (lives far from me), etc.

Other characteristics:
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Skills
What makes you feel equipped to deal with these peoples’ questions or suspicions about your HIV status?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Do you feel equipped to deal with these people’s questions or suspicions about your HIV status?

☐ Yes  ☐ No

If these people were to "out" you, how would you react to this breach of confidentiality?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Continued on the next page...

One, Two, Three, HUSH!

My Secret Recipe

Support
Did anyone pressure you to make this decision?

□ Yes □ No

What supports do you have to help you with this decision?

_______________________________________________________________________
_______________________________________________________________________

Strategies
What strategies do you use to keep your secret from these people?

It is feasible for you to keep your secret from these people if you use these strategies?

On a scale of 0 to 5, indicate to what extent you feel that each of these strategies is feasible.

<table>
<thead>
<tr>
<th>Strategies</th>
<th>Not feasible at all (0)</th>
<th>Very feasible (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>0 1 2 3 4 5</td>
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<tr>
<td>2</td>
<td>0 1 2 3 4 5</td>
<td></td>
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<tr>
<td>3.</td>
<td>0 1 2 3 4 5</td>
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<tr>
<td>4</td>
<td>0 1 2 3 4 5</td>
<td></td>
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<tr>
<td>5.</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

Continued on the next page...

One, Two, Three, HUSH!

My Secret Recipe

Well-being

How do you live with your secret?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

How does keeping your HIV status affect you in your daily life?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

How do you cope with your secret?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

What are your tricks?

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Indicate other ingredients that you think you should add to your recipe.

_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________


Disclosure
Strategy Card

- Checking into people’s attitudes about HIV and people living with HIV
- Talking to a healthcare provider (social worker, therapist, counsellor...)
- Taking your medications in private ....
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________
- ___________________________________

I Can Live with My Secret

- Using their logbook, the participants illustrate or write how they can lighten the burden of their secret or better manage it by being more comfortable with their HIV-positive status.
- The participants are encouraged to use their imagination.
- Ideally, the participants should have access to magazines, newspapers, stickers, cardboard, scissors, etc.
- If there isn’t much time left for the review activity, the facilitator can ask the participants to give just one word that stuck with them during the exercise.

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”
- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and log-book in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Meeting 8: Participants’ Messages

Required Materials for the Meeting

- A logbook for each participant
- Participant binder/duo-tang
- A large piece of cardboard or a large piece of fabric/paper (to make the mural)
- Scissors for each participant
- Glue sticks
- Coloured pencils, crayons or markers + Various magazines
- A device to play music
- A selection of music
- “My First Page” completed activity from Meeting 1: Welcome; for review

Review of “My First Page”

- The facilitator asks the participants to take out their “first page,” which they completed during the first meeting of the program (the welcome meeting).

- The facilitator asks the participants to take turns sharing what they learned during the program and how this ties into what they wrote on their first page (what they hoped to get out of the program).
  - “What did you get out the program?”
  - “Would you say that the program met your expectations?”

- Given the nature of the activities involved in this final meeting, let the participants know there will be no scheduled break but that each participant can take a short break at some point if they feel the need.
Participants’ Messages

- This activity may vary depending on the number of participants and the amount of time the participants spend on it.
- For this exercise, it would be helpful to guide the participants as they create the group mural. The facilitator can draw inspiration from the content details in the box below.
- The facilitator can also play music to create a more relaxing and creative atmosphere.
- The facilitator asks the participants to think about the question below:
  - “What message would you give to other women living with HIV who have concerns surrounding the disclosure of their status?”
- The idea is for the participants to COLLECTIVELY create a message of solidarity with other women living with HIV.
- The participants then draw and write down their thoughts or messages using the materials provided by the facilitator (cardboard, fabric, canvas, etc.).

What are the objectives of the group mural?

1. To develop a positive sense of belonging within the group.
2. To allow the participants to express their message of solidarity through art.

How can group artwork be created?

- To make this effort successful, the facilitator should encourage the participants to:
  - use their imagination
  - work together
  - respect others’ ideas and ability to do this type of creative exercise
  - come up with strategies that will promote teamwork (e.g., one person can write, another can draw, another can look for images from the magazines provided, etc.)
- The facilitator should emphasize to participants that they don’t need to be artistic to work on this activity and that everyone’s contribution is essential.

Continued on the next page...

The steps involved in making the mural:

Step 1: Inspiration
- The participants should reflect on the theme of the mural (messages to people living with HIV who have concerns surrounding the disclosure of their status) and think of a message they would like to convey.
- For this step, the participants should determine the message as a group.
- Once they determine the message, they find words, colours, shapes or images from magazines that they can use to express this message.

Step 2: Development
- The participants draw, write, colour or paint the message they want to express using markers, paint and images.

Step 3: Observation
- The participants look at the mural to ensure that the people they are creating it for will intuitively understand their message and know that they are supported.

Step 4: Final touches
- If they wish, the participants can choose a background colour. While some of the participants work on part of the mural, others can paint the background or help those who have not finished their part. Fifteen minutes before the end of the activity, the facilitator tells the participants how much time is left to complete the mural.
- The facilitator can also work on the mural with the participants.
- The facilitator asks the participants what they think of the group mural.
- Where applicable, the facilitator can ask the participants’ permission to take a few pictures of the mural, which may be published on the organization’s website to promote the program.
- With the participants’ help, the facilitator hangs the mural on a wall.

Potluck and Final thoughts on the Program

- While the participants share the potluck meal, the facilitator asks them to express what each group member has taught them. In closing, the facilitator asks the participants to suggest other themes they would have enjoyed exploring.

- The facilitator can write the participants’ statements on a piece of paper or on the board. This exercise allows the participants to talk about the new skills, beliefs and attitudes they learned from each other.

- The additional themes the participants suggest could also guide program improvements or could be considered as subjects to be explored in future group meetings.

- If the organization and its resources permit, tell the participants they can continue to meet whenever they wish. They could create an informal support group where they could get together over coffee to chat or further explore subjects discussed during the program meetings.

- The facilitator suggests that the participants stay in touch and exchange contact information so they can support each other in the future.

- The participants can also assign one of themselves to serve as a resource person that the others can call on for support and comfort, if they need it.

Closing Activity: Thoughts About the Meeting

- After the meeting, the facilitator asks the participants,
  - “How do you feel?” / “What are you feeling?” / “What’s going on inside of your head?”
- The facilitator gives each participant around 2 minutes to express their feelings.
- The participants can be asked to answer the question using a word, feeling, colour or number (e.g., expressing emotions on a scale from 0 to 10 to specify its impact).
- The facilitator can then ask the participants to elaborate if appropriate.
- Give the participants a few minutes to talk if they feel uneasy.
- This exercise is an excellent opportunity for the participants to express how they feel and for the facilitator to get a sense of their state of mind after the meeting and offer them support, a support referral, or schedule an individual meeting to talk.
- The facilitator asks the participants what they liked about the meeting and what they didn’t like as much. Where applicable, the facilitator can also ask them what part they liked the best (their favourite part) and if they have any suggestions for improving the meeting.


- The facilitator can write the participants’ comments on a piece of paper or on the board. These statements can be used to help improve the content, form or structure of the program.
- Inform participants about the next meeting (time, date, and location) and the meeting’s theme.
- The facilitator reminds the participants they can keep their activity sheets and logbook in their binder/duo-tang.
- The participants are asked to think about what they learned during the meeting and to integrate it in their daily lives.

Resources

- “Disclosure: Telling someone you are living with HIV”
  - https://positivelivingbc.org/resources/health-resources/
- “Workshop: Skill building in disclosure of HIV diagnosis”
  - http://www.womenchildrenhiv.org/wchiv?page=pi-17-02
- “Children and HIV”
- “Is formula good for my baby?”
- “Know your rights”
  - http://www.aidslaw.ca/site/kyr/
- “HIV testing handbook: A guide to your rights”
- “HIV disclosure and the law: What you need to know”
- “HIV disclosure: A legal guide for gay men in Canada”
- “Criminal law & HIV non-disclosure in Canada”
- “HIV disclosure to sexual partners: Questions and answers for newcomers”
  - http://www.aidslaw.ca/site/hiv-disclosure-to-sexual-partners-qa-for-newcomers/
- “Citizenship and Immigration Canada: Procedure for HIV Positive Cases“
- “What should people living with HIV do if they are concerned that they may be under investigation for allegedly failing to disclose their HIV-positive status?”
Resources

- “Canadian HIV/AIDS Legal Network”
  - http://www.aidslaw.ca/site/
- “HIV & AIDS Legal Clinic Ontario”
  - http://www.halco.org/
- “Sharing together for life: Facilitator’s guide”
  - http://www.catie.ca/sites/default/files/sharing-together-for-life_0.pdf
- “Sharing together for life: Webinar”
- “HIV disclosure and the law: A resource kit for service providers”
- “Legal and clinical implications of HIV non-disclosure: A practical guide for HIV nurses in Canada”
- “Responding to the criminalization of HIV transmission or exposure: Resources for lawyer and advocates”
- “Mental illness, criminal offences, and deportation”
- “Rapid response test 2”
  - http://www.ohtn.on.ca/rapid-response-test-2/