Disclosure of HIV-positive status: Towards the development of guidelines, strategies and interventions

Questions

- What are the facilitators and barriers to people disclosing their HIV status?
- What are the impacts, consequences and outcomes of disclosing?
- What are effective strategies for disclosing?
- What are effective interventions to guide disclosure?

Key Take Home Messages

- HIV disclosure is a lifelong process. Reasons for disclosing/not disclosing change constantly. Many individuals have their own personal strategies and reasons for disclosing, which are carefully planned to elicit positive outcomes.
- Common facilitators/reasons for disclosing are: trust in the person receiving the disclosure; positive experiences with previous disclosure; existence of strong social support; to gain social support; to relieve the stress of keeping their HIV status a secret; obligation and duty to inform; self-acceptance of HIV-positive identity; to share knowledge; and to control disclosure (i.e. to disclose before someone else exposes them).
- Common barriers to disclosing are: negative experiences with previous disclosures; fear of discrimination, stigma and rejection; lack of a strong social network; feelings of shame and guilt regarding one’s HIV status; struggle with HIV+ identity; cultural factors (e.g. homophobia) within one’s community; lack of HIV education and inability to cope with the outcome of the disclosure; and concern about harming or burdening others.
- The impacts and outcomes of HIV-disclosure are wide-ranging. Negative outcomes include: rejection, abuse, violence, stigma and discrimination. Positive outcomes include: more high quality social support, stronger family cohesion and relationships, reductions in anxiety and depression, and improvements in physical health. Most studies found more positive outcomes than negative ones, particularly over the long term. Furthermore, the majority of people who have disclosed reported little to no regret post-disclosure.
- There have been few studies examining interventions targeting HIV disclosure. Of the interventions reviewed, those that guided HIV-positive individuals through an introspective process, and helped them develop a disclosure plan and the skills to communicate their status, were found to be most effective in increasing disclosure, and improving disclosure outcomes.

Suggested Citation:

Prepared by:
Sanjana Mitra
David Gogolishvili
Jason Globerman

Program Leads / Editors:
Jason Globerman
Sean B. Rourke, PhD
Jean Bacon

Contact:
rapidresponse@ohtn.on.ca
The Issue and Why It’s Important

Disclosure is something that every person living with HIV experiences and struggles with. The process is complex and fraught with mixed emotions, and the outcomes can be unpredictable and difficult to handle. Despite the difficulty disclosure might pose, non-disclosure has detrimental impacts on the person living with HIV and is associated with personal distress, loneliness and social isolation.(1–4) Furthermore, non-disclosure may lead to medical non-adherence as a way to conceal the disease from others.(5;6) Not only is disclosure important for the person living with HIV, it is also important for those around him or her. For example, children who are unaware of their mother’s HIV-status can often perceive that something is wrong and become distressed when they are unable to express their feelings.(7;8)

In the context of society and community, disclosure is thought to be important for public health purposes in terms of preventing the spread of HIV. Furthermore, non-disclosure of one’s HIV-positive status before engaging in a sexual act can lead to criminal prosecutions in Canada and elsewhere. Given the personal, societal and legal importance of HIV disclosure, it is important to understand the experiences of HIV disclosure, as well as effective disclosure strategies and interventions for people living with HIV.

What We Found

We found the following studies, reviews and dissertations addressing the four research questions: three reviews (a literature review, a systematic review and a meta-analysis) that summarize the evidence related to facilitators and barriers to HIV disclosure; articles or dissertations on the impact, consequences and outcomes of disclosure; articles or dissertations exploring disclosure strategies; and articles examining interventions developed to increase and/or improve HIV disclosure. Most papers examined were based on findings and experiences of specific populations (e.g. men who have sex with men, heterosexual persons, people who use drugs, women and, more specifically, mothers, ethnic/visible/racial minorities), and on disclosure events and outcomes with a specific target audiences (family, children, friends, sexual partners and in the workplace). However, despite the population differences, many of the findings were common across all groups.

Facilitators and barriers to disclosing HIV-positive status

Trust was the overarching theme and core value for disclosure among people living with HIV. When deciding to disclose, the idea and feeling of ‘trust’ comes into play in many ways. For example, individuals may only disclose if they feel that the person receiving the disclosure can be trusted to keep their HIV-status information private.(5;9–11) More importantly, the act of disclosure requires the HIV-positive person to trust that he or she will not be ostracized, criticized, stigmatized or rejected after the event.

Aside from trust, the decision to disclose one’s HIV-positive status depends largely on the perceived benefits and whether those benefits outweigh the potential risks and harms. Many perceived benefits and harms of disclosing – which act as facilitators and barriers – can be loosely categorized based on three objectives a person may have: instrumental goals, identity goals and relational goals.(12)

Two common instrumental goals of disclosing one’s status are to gain information and to seek support, emotional and practical, from inside or outside one’s social network.(5;9;12–16) Literature shows people with HIV tend to disclose more frequently to family and relatives than to friends, and to steady/long-
term/monogamous partners more often than casual partners, perhaps because of the perceived probability of gaining support as well as the inherent level of trust.(5;9-11;13) Disclosing to seek support is most likely when the individual perceives a strong social network (6) and less likely when he or she feels socially isolated.(17) People living with HIV may also disclose in order to the find relief from the stress of keeping a secret (9) or to share knowledge about the disease with others.(13) People with HIV tend to make fewer disclosures immediately after diagnosis. However, the frequency of disclosure as a mechanism to cope with the disease generally increases over time as the person gains increased self-acceptance and knowledge of the disease, and greater capacity to cope with disclosure.(9;13) Some instrumental goals that affect the decision to disclose are unique to specific populations. For example, a person who injects drugs might avoid disclosure due to a fear of loss of income and drugs.(6)

Non-disclosure is often a mechanism to achieve a person’s identity goals,(12) which might be to maintain a positive identity and avoid stigma and discrimination.(7;18) Fear of stigma, which can be exacerbated by constricted social networks, can compound the difficulties faced by people with HIV who have limited social support.(2) Perceived stigma is associated with an individual’s self-acceptance of their HIV status and overall perception of self: if they haven’t come to terms with their disease and feel shameful or guilty, then they would be unlikely to talk about it with others.(9;19-22) On the other hand, someone with HIV might choose to disclose in order to avoid second-hand disclosure (someone finding out from someone or somewhere else), which has a higher likelihood of affecting their identity and create regret.(8;13;23) People with HIV who are members of racial/visible/ethnic minorities report more perceived and real stigma than white populations, and some studies have shown they disclose to fewer people.(3;9;24;25;25) Cultural norms specific to different communities may dictate different responsibilities related to disclosure. For example, in Asian communities, the norm of collectivism dictates that disclosure of one’s HIV-status affects not only the individual but also his or her family. In some cases, non-disclosure is a way to avoid embarrassing the larger family and community.(3)

Relational goals – to maintain a friendship or relationship bond (12) – may encourage individuals to either disclose or conceal the fact that they have HIV. Most people living with HIV share a common concern that disclosure may harm a relationship and lead to rejection.(5;7;16;17;26;27) Some people worry that their disclosure might harm the person receiving the disclosure. For example, mothers may worry about burdening their children with their disease.(27) On the other hand, people living with HIV may sometimes decide to disclose their status as a way to reconcile and reconnect with friends and family members with whom they may have strained relationships due to their sexuality, history with addictions or other reasons.(13) They may disclose to feel closer to someone or because they feel a sense of obligation and duty to inform.(5;11;13)

The decision to disclose is highly complex and goes beyond the aforementioned goals. For most individuals, before even contemplating individual goals and objectives, and weighing the potential benefits and harms, the decision is very much informed by their own knowledge about HIV – and therefore their ability to cope with the disclosure process and its outcomes (addressing questions and concerns) (26;27) – as well as by their past experiences with disclosure.(5;13;17;19;26)
Impact, consequences and outcomes of HIV disclosure

The outcomes of HIV disclosure can be stressful but also rewarding. There isn’t a ‘rule of thumb’ for when outcomes or consequences might be positive or negative but, overall, evidence suggests positive reactions to disclosure outweigh negative ones. (5; 17) Studies have found very few people with HIV who reported regret related to previous disclosures. (20; 23; 28; 29) If they do have regrets about any disclosure event, those regrets generally fall into six categories: lack of preparation; poor timing; wrong context or setting; unsatisfactory content; second-hand disclosure; and negative outcomes. (20; 23)

Overall, negative reactions from family, friends, employers and the community were relatively low, ranging from three to 15% of reported disclosures. (9; 30) On the contrary, studies have found high levels of supportive reactions after disclosure across diverse settings. (9; 17) Common immediate reactions to disclosure include: shock, fear, anger, violence, explicit or implicit advice, emotional or instrumental support, relationship assurance (“we’ll always be friends”), acceptance and rejection. (12; 31) Disclosure can disrupt relationships with families and communities. It can also lead to rejection by friends and close ties, separation from partners, abuse, criticism, ostracism and isolation. (9; 26) Negative reactions are more likely if the person with HIV was perceived as being responsible for becoming infected and if the person (particularly women) has a history of abuse, drug use and low socioeconomic status. (9; 32) However, in most cases, these immediate reactions undergo positive changes. (31) Even if the initial response was shock, anger or disappointment, strong relationships are not impacted over the longer term and remain intact. (30; 33)

For many individuals, disclosure helps them gain higher levels and better quality of social support. (2; 7; 9; 15; 24; 27; 33-36) However, in contexts where there is a high level of stigma, the association between disclosure and social support is weaker. (9) Social support can be emotional or practical: emotional support includes expressions of concern and acceptance, and practical support includes financial or housing support and assistance with medical visits. (24) In a Greek study of the experience of people living with HIV disclosing to ‘close family,’ (35) the relationships that provided the most support were those with friends, lovers and partners, whereas fathers and children provided the least support. For young minority men who have sex with men, a recent study found that disclosure to sex partners and boyfriends was associated with safer sex practices including increased condom use during both oral and anal sex. (37)

In addition to obtaining social support, disclosure often has positive benefits in terms of the person’s physical and mental health. A systematic review (38) found that social support was consistently associated with better medical adherence so disclosure – because of its ability to engender social support – should also lead to better adherence. Some research evidence shows a direct link between HIV disclosure and better medical adherence, however this relationship is mediated by the amount and quality of social support. (6; 39; 40) Those who have disclosed report lower levels of emotional distress, depression and anxiety than those who have not, although this relationship depends largely on the level of social support garnered from disclosure. (1; 4; 5; 7; 27) Disclosure has been found to strengthen relationships and improve family cohesion, perhaps because of the increased level of trust and comfort to confide. (7; 8; 26; 27; 30; 35; 41) In long-term relationships, the disclosure process is an act of honesty and integrity that improves a relationship in healthy situations: (26), however, poor (unsupportive, strained or abusive) relationships are rarely strengthened and often worsened by disclosure. (30) In those situations, disclosure can lead to increased stress and poorer psychological wellbeing. (30; 42)
Mother-to-child disclosure

Many studies specifically examined the experiences of mothers with HIV disclosing to their non-infected children. Their findings were consistent with studies on other populations, which include: improved health, and reductions in stress, depression and anxiety for the mother, and improved family cohesion.(7;29) Children report strong negative emotions of shock and fear at the actual disclosure event (41) Older adolescent children have poorer reactions and more problematic adjustment post-disclosure than younger children.(27) Children report more anxiety when the mother is visibly ill at the time of disclosure.(27) But over time, as children become more informed about the disease and their mother’s health, most adjust well and experience reductions in depression and anxiety, as well as increases in involvement and happiness.(7;27;29;41;43;44) Overall, only a very small percentage of children become maladaptive and act out over time.(7;43) It is important to note that children who are sworn to secrecy and who have nobody to talk to about their mother’s illness tend to demonstrate more externalizing problems and poorer social competence.(7;29;45)

Workplace disclosure

Disclosure in the workplace can create great stress in people living with HIV but it is often necessary for people to access necessary accommodations, such as reductions in work load and time off for medical visits or ill health. The challenge of workplace disclosure is becoming more prevalent as, with the advent of highly active antiretroviral therapy, more people living with HIV are enjoying better health and seeking or maintaining employment.(46) Only three studies and reviews included in this report examined disclosure experiences in the workplace specifically.(6;46;47) They found that most people with HIV who are employed have not disclosed their status. Those with poorer health, who were visibly ill or had symptomatic AIDS were more likely to have disclosed than those who were healthy.(6;46) As with other forms of disclosures, the main deterrents are concerns about stigma, harassment and discrimination in the workplace. These concerns are stronger in workplaces that are less supportive and less educated about HIV and when the person with HIV does not have strong bonds with co-workers. These concerns are often heightened by how ‘public’ workplace disclosures can be.(6;46) Despite the small proportion of people with HIV who reported full or selective disclosure of their HIV status in the workplace, most of those who did disclose reported positive experiences: better workplace accommodations; supportive reactions from coworkers and supervisors; and less stress from concealing their illness.(6;46) Carefully planned workplace disclosures led to more positive consequences than anticipated – including fewer terminations and more supportive reactions than expected before disclosure.(6)

HIV disclosure strategies

Careful planning and preparation for a disclosure increases the likelihood the person will receive positive reactions and achieve his or her disclosure goals. The planning process includes decisions on: who to disclose to, why to disclose, when to disclose, where to disclose and how to disclose. Based on reported negative experiences, people with HIV advise against: disclosing because you feel pressured to; not planning before disclosure for both the actual event as well as coping with the outcomes; and disclosing too soon before dealing with personal emotions and feelings about the new diagnosis.(5;20;48)

Approaches to HIV disclosure fall under three categories: disclose to everyone, disclose to no one, and selective and strategic disclosure.(2;5;9;17) Those who choose to disclose to everyone face the highest risk of stigma and discrimination, but tend to be more prepared to deal with those negative outcomes, have a high sense of self-esteem and have a “take me as I am attitude.”(2;5) In contrast, those who disclose to no one have lower self-acceptance, less access to social support networks, greater fears and concerns of stigma, and face the highest risk...
of social isolation and loss of close personal relationships due to disease-related stress. (2;5;9) The selective approach to disclosure is most common among people living with HIV. (2;5;9;17) Disclosing and not disclosing are both ways of coping, and the decision depends on strategically weighing the benefits and harms for each disclosure event. There isn’t a single formula, and the decision differs for different targets of disclosure (e.g. friend, family, spouse) and in different contexts. Even though these approach categories are helpful in summarizing disclosure experiences, they aren’t static. Individuals’ disclosure decisions change constantly over time depending on their circumstances.

In the literature, effective and ineffective disclosure strategies discussed by people living with HIV are similar across contexts and settings. That is, what people recommend as effective for mother-to-child disclosure also applies to disclosure among other populations. Generally, selective disclosers will only disclose to those individuals who they deem are likely to have a positive reaction and will provide support, and to those who they feel they have a duty to inform (e.g. medical personnel, sexual and/or drug-using partners). Below is a list, from the literature, of strategies based on the disclosure experience of people living with HIV:

**Carefully decide who to disclose to:** When deciding whom to disclose to, individuals should assess: the type of relationship with the individual, the quality of the relationship and the perceived likelihood of confidentiality. (11;49) To help with this decision, individuals could make a disclosure list (30), which helps to assess one’s social network and “can be a validating experience for those with an adequate network”. Individuals who’ve prepared such a list often feel empowered by the number of high quality relationships with whom they trust to have positive disclosure experiences. (30) This list should be as comprehensive as possible, and should include everyone in one’s social network (e.g. friends, family, partners, colleagues, social workers, health care staff). Compiling a list is helpful for preparing for potential reactions. It is also useful for assessing the aspects of each relationship, and deciding whom to disclose to now (usually for support and to help build confidence), whom to disclose to later and whom not to disclose to.

**Probe, hint and “test the waters”**: When individuals are unsure what someone’s reaction to HIV disclosure might be, they might “probe their target for stigma and perceptions about HIV”. (5) Individuals might ask their disclosure targets if they know anyone with HIV, or what they think about the criminal law against non-disclosure of HIV. People who are knowledgeable about HIV or who know someone else with HIV tend to be more accepting. (30) Before disclosing, the person might also “set the stage” by providing ample hints – verbal, symbolic, listing HIV status online – to get an idea of how someone might react and to prepare the other person for their disclosure. (50)

**Seek similar individuals:** People with HIV may start off by disclosing to others who are living with HIV or who are allies of people with HIV. (16;50) "Disclosing to other HIV-positive people seemed to minimize feelings of stigma associated with disclosure to HIV-negative sexual partners. Furthermore, the support provided by these individuals seems to allay some of the negative consequences associated with disclosure.” (16) Individuals can also use this method to learn from other people’s disclosure experiences and share HIV knowledge. (13) Individuals with a limited social network or who wish to enhance social support from disclosure, might benefit from becoming more socially involved in the larger community through support groups, advocacy groups and community activities – particularly those related to HIV. (26)
Be sure to deal with personal feelings with diagnosis: Most successful and positive disclosure experiences start with self-acceptance of one’s HIV status. Having a positive self-image and perceiving – pre-disclosure – that people will react positively are associated with positive disclosure outcomes. Getting comfortable with and accepting one’s diagnosis, and understanding how it impacts one’s life, are important steps to gaining the confidence to cope with disclosure. Being comfortable with one’s HIV status includes being able to answer questions someone might have after receiving the news and being able to provide emotional support for the person receiving the disclosure when needed. If the person living with HIV is struggling with their identity, then they are likely to be “less adept at communicating information about their diagnosis and eliciting a positive reaction.” One suggestion for people struggling with their HIV status is to participate in expressive writing and therapeutic settings to process their diagnosis-related thoughts and feelings.

Educate self and others: The first step to self-acceptance and successful disclosure is education. People with HIV should learn as much as possible about the diagnosis and how it affects themselves and others. Self-education about HIV/AIDS – by talking to health care professionals, talking to other people with HIV, reading and attending conferences – helps to empower individuals so they feel more prepared to disclose and share information about their diagnosis. Being readily able to provide information, assurances and answers about one’s diagnosis can alleviate stress and anxiety and increase the likelihood of positive adjustment during and after disclosure. One strategy that mothers with HIV found useful was to disclose in two stages: start the disclosure process by teaching age-appropriate concepts about HIV to their children and only proceed to disclose when the child seems to be ready for the news.

Be clear on why you are disclosing (to the target person): Knowing the reasons for disclosure helps tailor the message in order to accomplish desired goals and achieve more positive outcomes. Is the reason or goal for disclosure to gain emotional or practical support? Is the disclosure due to a sense of obligation or duty to inform? Knowing why one is disclosing can also help set limits and boundaries to how much information to share when disclosing; not setting these boundaries at the outset could increase distress and anxiety during and after disclosure.

Deliberate over the most appropriate time and setting: People living with HIV should avoid blurtling out the news. Unplanned disclosure often leads to significant regret. It is wise to consider when the best time to disclose is. First, the individual should assess his or her own mental state and feelings. Only when the person is in a good mood and feels prepared should he or she disclose. Second, the person should also consider the mental state and any special circumstances of the person receiving the disclosure (e.g. Did they just lose someone close or become unemployed? Are they too young or too uneducated on HIV issues?). If the mental states of both parties are positive and stable, then the individual should also consider their own health. Disclosures tend to be more positive and less stressful when the disclosing individual is healthy. If possible, disclose before the disease has entered an advanced stage, which would be less stressful for the person receiving the disclosure and allow him or her to prepare for the person’s future health changes. Other considerations of time and place include:

- should other people be present (health worker or other family members, for example)
- avoid disclosing late in the evening or when the recipient is tired

References:
50. Serovich JM, Oliver DG, Smith SA, Mason TL. Methods of HIV disclosure by men who have sex with men to casual sexual partners. AIDS Patient Care STDs 2005 December;19(12):823-32.
• avoid hurried, crowded, noisy or distracting situations.

Choose the appropriate method: Most disclosures are face-to-face. However, sometimes disclosure can happen in writing (e.g. when the person receiving the disclosure is far away, when someone feels they communicate better through written words, when the person wants to avoid disruptions or the stress of rejection in a face-to-face-encounter). Disclosures can also occur online or over the phone, among many other methods. Individuals should choose the most suitable disclosure method based on their own and the recipients’ circumstances.

Tailor the disclosure message and content appropriately: The type and quality of a relationship, the age of the recipient, the recipient’s knowledge and understanding of HIV/AIDS, and the person’s goals and reasons for disclosing are all important considerations for what to include when disclosing. One study provided a class of undergraduate students in a Midwestern university with hypothetical disclosure messages, and found that some ways of revealing one’s status is likely to be viewed more favourably than others. Disclosures with a plain, direct, blunt message, such as “I have HIV,” are more likely to elicit negative emotions of sadness and fear. However, a simple message also yielded more emotional support, advice and a feeling that disclosure made them feel closer to the disclosing individual. Messages that sought support, such as “I am going through a really hard time right now and could use your support. I was recently diagnosed with HIV,” led to higher levels of support and concern, and relatively low levels of blaming.

On the other hand, messages that asked for assurance of privacy (“Don’t tell anyone else, but I have HIV”), or sought for relational assurance (“Please don’t let this affect our friendship, but I have HIV”), or mentioned the recipient’s right to know (“I’m telling you this because I think you have the right to know”) were more likely to lead to negative reactions, including blaming, a diminished sense that a relationship will be closer, less comforting and less emotional support.

External support: Seeking help from others, such as health and social workers, can help individuals cope with disclosure and its aftermath. As Rodkjaer et al. (2) observed: “The infected person might benefit from a systematic and ongoing discussion of all the issues linked with disclosure to reduce the stress and depressive symptoms, focusing on what puts the person off balance rather than thinking of risk factors to adopt a more healthy disclosure strategy to stay in balance.” External help could be emotional support through the disclosure planning process or practical support for planning and implementing disclosure (e.g. role-playing, practicing the disclosure, brainstorming potential reactions). It could also help both the person with HIV and the person receiving the disclosure.

Strategies and advice specific for HIV-positive mothers planning disclosure to children: Although many of the advice and strategies offered for HIV-positive mothers planning disclosure can be translated to other populations and audiences, there are some unique to this group: Prepare a ‘safe list’ of people their children can talk to after disclosure to relieve the stress caused by secrecy.

• Make the disclosure personally and do the actual explaining to the child – although another person can be in the room for support.
• Control your emotions and demeanor – stay calm and natural.
• Provide emotional support and reassurance throughout the disclosure process to reassure the children and dispel their fears.
• Plan appropriate psychological follow-up for the children so they have an opportunity to discuss their concerns and fears. Seek professional support
after the disclosure to increase the venues through which the children can address their anxieties. (20; 43)

- Introduce children to other healthy mothers living with HIV so they know they’re not the only ones coping with this illness, and they can see other mothers living healthy productive lives. (20)

**HIV disclosure interventions**

Interventions to promote HIV disclosure cannot be understood without considering the social and environmental context within which relationships and behaviours (sexual or otherwise) are negotiated. Interventions should acknowledge HIV-related stigma and marginalization of certain populations due to race, gender and sexual orientation, as stigma influences the likelihood of disclosure. (52; 53)

We found nine studies examining specific interventions (7; 28; 54-57) and one review examining and comparing thirteen HIV Prevention with Positives (PwP) interventions in the United States (58). Of the nine primary studies, six of them were effective in promoting disclosure and improving disclosure processes and outcomes:

- a 4-session intervention for helping mothers living with HIV/AIDS disclose to their children (The Teaching, Raising and Communicating with Kids (TRACK) program); (7)
- a four-session intervention designed to assist in the planning and preparation for disclosure to family among HIV-positive men who have sex with men (MSM); (28)
- a 9-minute video drama called “The Morning After” that was “designed to promote critical thinking about HIV disclosure, HIV testing, alcohol use, and risky sexual behaviours” (54);
- a 10-session HIV prevention intervention for HIV-positive heterosexually active injection drug users, which was designed as a highly practical forum for participants to practice disclosing skills and the language for doing so (57);
- an 8-session of family group psychotherapy with HIV positive parents and their children (59);
- a 3-phase brief disclosure intervention for HIV-positive African Americans. (61)

Each of these interventions utilized practical components to help individuals plan for their disclosure: role-playing and behavioural exercises, discussing and thinking about what needs to be considered prior to disclosure, developing communication (and parenting) and language skills applicable to disclosure, and preparing for potential reactions and outcomes to disclosure. The critical thinking, introspective and practical elements were common across these interventions and important to their success. This finding is similar to that observed by Frye et al. (58) in their review of 13 PwP interventions in 13 different clinical/medical settings in the U.S: “The opportunity to develop communication skills and strategies to disclose, reflect about living with HIV, explore fears of rejections and explore a sense of responsibility were topics that influenced patients’ intention to disclosure and their disclosure practices. Intervention pathways that influenced disclosure provided patients with an opportunity for introspection, increased support, discussing stigma and developing skills to disclose.”

On the other hand, the three interventions that did not lead to significant differences or improvements in disclosure and disclosure outcomes did not include those elements. They were: an intervention to increase HIV status disclosure and condom use among women living with HIV/AIDS (56); a primary care clinic tested computer-assisted, provider-delivered intervention among HIV-
positive men who have sex with men (60); and a disclosure intervention for men who have sex with men comprised of small group sessions facilitated by HIV-positive peers.(55) Wolitski et al. (55) suggest that the lack of effect on disclosure from their peer-led intervention might be because these group sessions “inadvertently exposed lower-risk participants to beliefs of higher-risk group members that were inconsistent with the intervention. These discussions may have created negative role models whose beliefs and behaviours were inconsistent with those communicated by the peer facilitators.”

Finally, there is a call for sociocultural and structural interventions that promote anti-discriminatory legislation which creates a safe atmosphere for disclosure.(53)

**Factors That May Impact Local Applicability**

The majority of the studies were conducted in North America. A few were conducted in other high-income contexts. Thus, the reported experiences and summarized evidence are likely relevant and similar to the experiences of people living with HIV in Ontario and Canada. However, it is important to note that context plays an important role in disclosure planning, implementation and outcomes, and thus disclosure preparation and results can vary from person to person, and from community to community.

**What We Did**

For the original review we searched Medline using a combination of MeSH term HIV AND either MeSH term Self Disclosure or Disclosure or Truth disclosure, or keyword Disclosure. We also searched PsychInfo using a combination of MeSH term HIV AND either MeSH term Self Disclosure or keyword Disclosure. We also searched the Cochrane Library and SHARE (www.hivevidence.org), a synthesized research evidence database, for any relevant systematic reviews using the text terms HIV AND Disclosure. Lastly, we reviewed citations in Adam BD, Elliott R, Corriveau P, Travers R, English K. How criminalization is affecting people living with HIV in Ontario. Ontario HIV Treatment Network, 2012 and did a related article search in PubMed for Simoni JM, Pantalone DW. Secrets and safety in the age of AIDS: does HIV disclosure lead to safer sex. Topics in HIV Medicine 2004;12(4):109-18. All searches were conducted on February 2013 and results limited to English articles published from 2000 to present with a study jurisdiction in a high income country.

For the update we searched Medline and PsychINFO using a combination of MeSH terms for HIV AND Self Disclosure or Disclosure. The Cochrane Library and SHARE were also searched for the terms HIV AND Disclosure. All searches for the update were conducted from March 2013 to September 2013.

**Suggested Citation:**