

---

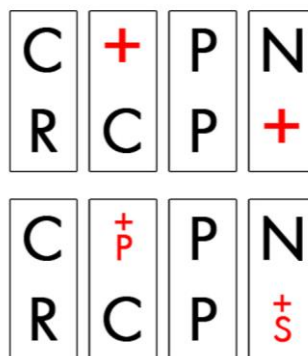
# HIV YOUTH DISCLOSURE PROJECT SURVEY RESULTS

---

Muluba Habanyama

Sarah Chown<sup>1</sup>

In collaboration with YouthCO<sup>1</sup>, the HIV Disclosure Project, and  
Canadian Positive People Network Youth Caucus



May 2016

## Introduction

In December 2015, YouthCO HIV & Hep C Society, Canadian Positive People Network Youth Caucus, and the HIV Disclosure Project collaborated in a survey for youth under 30 years old which focused on experiences of HIV disclosure. Youth living with HIV have previously identified wanting more supportive services and workshops to be available as supports as they navigate the complexities of disclosure of their HIV status to partners, family members and friends. Disclosure of one's HIV status is complex and has been identified in several reports and discussions with youth as a major stressor in their lives.

To date, there has not been a concrete resource available to offer youth in Canada a space to discuss disclosure issues. This survey is the starting point where information was gathered to identify the needs of youth and to gather their feedback as a workshop is developed to address disclosure complexities.

## Methods

The questions were developed and designed by youth who had lived experiences with HIV disclosure, in collaboration with the HIV Disclosure Project led by adults living with HIV, and HIV-negative staff at YouthCO who works with youth living with HIV. The survey questions were designed to gather as much information as possible about disclosure to adapt and develop tools and resources to support youth through the process to promote successful experiences and support youth in areas of disclosure that were deemed stressful and difficult.

The survey was available online between December 2015 and February 2016. YouthCO, CPPN, and the HIV Disclosure Project promoted the survey via general social media channels, and also shared this survey in Facebook groups of youth living with HIV. Participants were able to complete this survey anonymously.

The survey had two key sections – first, a section asking about experiences of HIV disclosure, followed by a section soliciting feedback and suggestions for a workshop to support youth with HIV disclosure. We asked a total of nine questions:

1. Could you tell us about an experience you have had disclosing your HIV status?
2. What were some of the things that went well in this experience?
3. What were some of the things that you did not like about this experience?
4. Can you think about a time when you wanted to disclose but were not able to, what stopped you?
5. What do you need to feel comfortable disclosing your HIV status?
6. What reasons do you have for disclosing?
7. What ideas do you have for a workshop on disclosure?
8. What is your idea for a title for the workshop?
9. What ideas do you have for a place for the workshop?

Youth were able to respond to each question with as many words as they wanted. Our team reviewed each individual response and identified key themes reported below.

## Results

Although 22 surveys were received through an anonymous online questionnaire, only 12 of the surveys were completed in full and used in the data analysis. Surveys were completed primarily by youth living in Ontario and British Columbia.

### Experiences of HIV Disclosure

Most youth (50%) chose to share an experience with disclosure of their HIV status that was positive. , 33% shared both negative and positive experiences with disclosing their HIV status. One participant shared a neutral experience; one participant shared a negative experience. In recounting an experience of disclosure, youth highlighted:

- Close friends and partners may be accepting of an HIV disclosure without knowing many facts about HIV
- Providing education about HIV to sexual partners as a part of HIV disclosure helped to promote acceptance
- Choosing a supportive environment for disclosure, disclosing HIV status in person helped, and sharing HIV facts with in everyday conversation prior to disclosure help to facilitate positive experiences
- Disclosing HIV status can lead youth to feel exposed, vulnerable, and uncertain
- Fear, stigma, discrimination and rejection are part of disclosure experiences
- Disclosure experiences can be frustrating, especially when taking on a role as the educator during HIV disclosure, and being treated differently like a "fragile being" after disclosure

Youth reported that disclosure is complicated, and often requires a lot of emotional energy before, during, and after.

When asked to reflect on positive aspects of their disclosure experiences, **all youth** were able to identify at least one positive aspect:

- Feeling closer to their partner/friend after disclosure
- Being able to acknowledge of vulnerabilities relating to HIV
- Feeling at ease after disclosure; a sense of closure
- Being careful about who to disclose to
- Finding support
- Prompting another person to get tested for HIV
- Clarify confusion, myths, and misinformation and address stigma related to HIV
- Honest, open conversations
- Disclosing while undetectable allowed support from others

**Only one youth reported no negative aspects or experiences** with disclosing their HIV status, and reported liking disclosure as it helped them to accept their own HIV status. However, 83% of respondents reported

negative aspects associated with disclosure. Many of these related to the ways the person that they disclosed to reacted, such as reacting with pity, being unsupportive, and having concerns about becoming HIV-positive and thus avoiding further conversations about HIV.

Participants also reported disliking the HIV stigma and stereotypes they encountered, fear that the person they told may spread the information through gossip, losing control of their confidential information, and frustration with the onus of both disclosing and educating.

100% of respondents shared situations in which they were prevented from disclosing their HIV status despite wanting to do so:

- Anticipating prejudice or rejection from individuals or a group, including concern for their own safety
- Short-term nature of a relationship (e.g. hook ups)
- Fear of being perceived as contagious
- Loss of control over their confidential information regarding their HIV status
- Concern for family's reactions, particularly older family members
- Concern that one had not yet reached the point of self acceptance and therefore could not expect others to accept them.

Youth identified a number of things that would help them to be more comfortable about disclosing their HIV status:

- practice at disclosing
- educating others so they can accept an HIV status
- Being able to mention an "undetectable" status
- Trust, faith, and understanding from others
- A safe exit strategy, either for the immediate situation or to change living situations (e.g. having a place to live and a job available in the event of a negative disclosure experience)
- Experience helping others to disclose their HIV status
- Being educated and well informed about HIV so they can explain it while disclosing to others
- Building self confidence to be able to disclose
- Support from family, friends, and community
- Trusting in others to keep the information of HIV disclosure confidential
- Psychological support

One youth said that they were already comfortable disclosing their HIV status and did not need any additional support or resources.

Reasons to disclose included:

- The feeling of being real and authentic with others
- Providing HIV education to partners, youth, and the public
- Reducing the possibility of passing HIV to doctors and dentists

- Connecting with, and/or offering support for other youth living with HIV
- Providing a role model to help people feel less hopeless, accept themselves, and be happy
- Feeling less different after disclosure
- Relieving a burden
- Promoting adherence to medication when burden of the secret is removed

## Suggestions for a Youth HIV Disclosure Workshop

In question number 7 92% of respondents put forth ideas for a workshop including - a focus on building self esteem, developing communication skills, strategies to cope with stigma and rejection, education on what "undetectable" means, HIV, unprotected sex and sex education for people living with HIV, training on HIV facts, a speaking circle where participants can learn more about strategies to cope with stigma, how to disclose and how to educate the public and take the messaging forward, open chair activity involving role play to develop disclosure strategies and strategies to cope with stigma, disclosing ones status, theatre, improvisation, a space to support each other, discuss complex disclosure issues and share information, having youth who are confident enough to share their HIV status at a workshop, having a person living with HIV leading the workshop, learn strategies to start the disclosure conversation with others.

75% of respondents put forth ideas for a title of the workshop. Title suggestions included:

- Let's Talk
- Sex For Young Adults,
- A Piece Of Me
- Positive Minded People Workshop
- Young Voices
- Self Love
- Youth+
- Valuable Me
- Yes

Participants shared their ideas the workshop, including hosting it while camping or in a place that celebrates nature and life and creating a play out of the workshop material. Participants also specifically noted the workshop should be offered at Positive Living Society of British Columbia, Eve for Life (Jamaica), AIDS Committee of Toronto, and various community centers, local colleges, and schools in various urban, suburban, and rural communities.

## Themes

The major themes which were observed in the responses to questions were **strategies for disclosing HIV, education of people who are HIV-negative, and acceptance**. In addition, youth who completed the survey consistently discussed stigma, fear and concern about loss of control over sharing



their HIV status. Youth gave examples of both fearing and experiencing rejection and loneliness.

## **HIV Disclosure Strategies**

Stigma, fear, and loss of control were consistently given as reasons that deterred youth from disclosing their HIV status or as a reaction after they disclosed their status. Youth shared some strategies they used when deciding to disclose, including:

- testing out their audience by discussing HIV in general terms before deciding whether or not to disclose
- developing a safe exit strategy if disclosure did not go well
- choosing to disclose in a safe place

Youth also told us that they needed and wanted to learn new strategies for disclosing their status. Disclosure was viewed as a way of encouraging others to get tested for HIV, relieving themselves of a burden which led to more open discussions about HIV and normalizing the topic of HIV. Disclosure was described as a way of helping with self esteem, self acceptance and in turn having others accept their HIV status. Disclosure helped youth receive support from peers which in turn helped youth adhere to their medication.

## **HIV Awareness & Education**

Another theme that all of the participants talked about was the need for more awareness and education about HIV. Youth mentioned wanting education for themselves so they could give informed, accurate information to people they were disclosing to. They also discussed the need for continued general education for the public as a means of helping them to be less fearful of HIV and less stigmatizing. Educating the public would relieve youth of the burden of always being the one to be the "educator" while disclosing.

Education was deemed as a tool to help youth with their self confidence and self acceptance as they would be well prepared to answer questions in a self assured manner which would in turn put others at ease and help youth in being accepted and feeling less "different" than other youths, fitting in. Providing education to the public is essential to foster an environment where youth could experience acceptance, support and understanding of what it means to be living with HIV, without fear.

## **Acceptance**

Acceptance was identified by youth as a necessary component for successful. Acceptance was seen as the outcome of addressing stigma, developing disclosure strategies, and educating themselves and the general public about HIV. Acceptance could be viewed as the ultimate goal where youth could accept their status, relieve themselves of the burden of carrying a secret, gain confidence and in turn gain acceptance from the general public. Some suggestions for acceptance were role plays, theatre productions for the public, educational aspects in a workshop about what it means to be undetectable and ways to constructively cope with stigma and discrimination with the ultimate goal of removing stigma and discrimination and being accepted as a youth who was living with HIV, not dying or in need of pity. The themes throughout were interconnected and were seen as integral aspects for integration of HIV youth without the risks of stigma and rejection.

## Conclusions and Recommendations

There are striking similarities to adult disclosure issues with the results of the survey questionnaire, as adults report the same themes and struggles which are identified by youth. While acknowledging the small sample size of the survey, it none the less produced data which was informative enough to demonstrate clearly the complexities of disclosing ones' HIV status.

Respondents identified the positive outcomes of sharing their HIV status in what it means to be a youth living with HIV. Yet stigma, fear and loss of control over ones' confidential information as well as concerns for safety issues and backlash remain obstacles to reaching a level of acceptance from the general public. Youth identified ways in which disclosure would ultimately lead to lower transmission rates of HIV, an increase in youth getting tested for HIV and how the need to have HIV become part of everyday conversation would invoke understanding, acceptance and support from peers and the general public.

Youth identified the need to not only educate youth to enhance their confidence and self esteem, but also to educate the public. Many youth reflected on the challenges of playing an educator role in the moments following disclosing their HIV status, and believed greater general education and awareness would ensure education could be a shared responsibility.

It is recommended that youth be given a space to discuss disclosure and develop disclosure workshops to receive education to enhance self esteem and confidence and to practice disclosure strategies with peers who are living with HIV. Discussing strategies would include safety issues for youth as they develop confidence in disclosing at a time and place that is safe for them, while developing exit strategies if disclosure is not successful. The workshops would focus on strategies to reach out to the public to educate with the goal of ultimately experiencing acceptance and understanding of HIV, eliminating the burden for youth living with HIV and as youth described lowering transmission rates of HIV and encouraging others to get tested for HIV.