



# HIV Made Me Fabulous

A short film about living and loving as a woman with HIV

FILM FACILITATION GUIDE





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## **VIEW THE FILM**



#### MEASURING THE IMPACTS OF FILM

Please watch and share our film and complete our survey to let us know your thoughts and feelings about the film. Please download our facilitation guide and host a screening in your community, and let us know the outcome by emailing the co-Principal Investigators of this project, Dr. Allison Carter (acarter@kirby.unsw.edu.au, based in Sydney, Australia) and Dr. Angela Kaida (angela kaida@sfu.ca, based in Vancouver, Canada).

Scan this QR code using your smartphone or tablet's camera, or visit <a href="http://lifeandlovewithhiv.ca/film">http://lifeandlovewithhiv.ca/film</a>.

Please use the below citations when referencing the Film Facilitation Guide or the film:

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## Introduction



#### ABOUT THE FILM

<u>HIV Made Me Fabulous</u> is a 10-minute film that tells the personal story of Juno Roche, a writer, activist, and trans woman, who has been living with HIV for over 25 years. Grounded in HIV science, the film examines issues related to HIV, <u>intersectionality</u>, and health equity. The film utilises embodied storytelling, which is an arts-based method that incorporates movement and dance to connect the viewer physically and emotionally to the story<sup>1</sup>. The film features voice-over narration by Juno Roche and three performers who represent Juno's story visually.

During the film, the women prepare to meet a potential lover, find the courage to knock on their door, and ride the emotional journey that ensues. Despite the women's different circumstances and backgrounds, they are connected by their living experiences of HIV. In watching, the viewer experiences the physical embodiment of Juno's story and the performers' emotions through their movements – by how they dance, how they walk, what they do, and even how they breathe.

The script and story of this film was created in collaboration with Juno Roche and Producer and Director Edmond Kilpatrick. Over a series of long, intimate discussions on the phone, the two shaped the story by exploring Juno's past and present and connecting those experiences to the body. From these conversations, a narrative for Juno and the actors emerged to become the basis for *HIV Made Me Fabulous*.

Please note that the film is intended for mature audiences.

#### ► ABOUT THE FACILITATION GUIDE

#### Who This Guide is For:

We invite everyone to share this film and its facilitation guide with their networks. Whether you are a person living with HIV, health care worker, community advocate, policymaker, social service provider, sexual health educator, researcher/professor, or member of the public – we encourage you to watch and learn from the film and host screenings and discussions with your community.

### Why This Guide Was Created:

We created this facilitation guide to foster respectful and affirming discussions about HIV and those who live with it, and to help individuals and organizations host successful film screenings that educate and connect viewers, allowing for deeper learning and exploration of topics and emotions arising from the film. By providing information to contextualize the film's themes and guidance on how to hold safer film screenings, we hope to maximize learning from and engagement with the film and its core messages.

#### How This Guide Works:

This facilitation guide includes guidance on how to host a screening, background information about HIV and sexual health, suggested discussion questions, recommendations for further action and additional resources. In the appendices, we have also provided a glossary of terms (which are underlined and hyperlinked throughout this document), screening checklist, agenda and optional handouts to share with audiences. We invite you to customize your screening using the information in this guide to best suit the needs of your audience.



# Using the Film Facilitation Guide

In this section, we provide in-depth guidance on how to host a screening that supports the safety of the hosts and viewers and promotes deeper discussion of the film. The guidance below can be adapted for both in person and virtual screenings. A screening checklist is provided in <u>Appendix B</u>.

#### CREATING SAFER SPACES

Some people may find the topics in the film inspiring, whereas for others, they may trigger difficult emotions. Taking the time to create a safer space is important to cultivate thoughtful, respectful, and productive discussion and can also help mitigate potential harm to viewers.

## Defining Principles for Safer Spaces:

At the beginning of your screening, it can be helpful to introduce a set of principles that the group will follow to maintain a respectful environment. Consider establishing a list beforehand with your team and dedicating time at the beginning of the event to discuss and revise them with attendees. To give you some ideas for your own list, you can refer to Appendix C for the set of principles that Elder Valerie Nicholson, a key advisor for this project, uses to gather in a safer space.

## Using a Strengths-Based Approach:

Another important aspect of creating a safer space is to approach these discussions through a strengths-based lens.<sup>2</sup> Rather than taking a deficit or negative view, as mainstream media and science often do about HIV, a strengths-based approach acknowledges and celebrates the strengths and wisdoms of women living with HIV as they navigate challenging social structures.

## Supporting Your Audience

The content of the film has the potential to upset viewers, particularly those who are living with HIV or who have experienced gender-based violence. We recommend you research resources in your area prior to your screening to share with audience members should they need more support. You can also set aside some time after your screening ends to debrief with those who need extra space.

#### SCREENING THE FILM

When organizing a film screening, consider following the practices described below to introduce the film and prepare attendees for the viewing. To help you plan your screening, we have attached a sample agenda (Appendix D) for a 90-minute film viewing and discussion session.

#### Introductions:

Introducing yourself as a facilitator is a good way to begin your session. You may like to give some background on who you are and how you come to this work, and perhaps allow attendees to introduce themselves as well. There should be no expectation of anyone to disclose their HIV status or other personal experiences.

## Land Acknowledgment:

In countries with a history of colonialism, a land acknowledgement is an important way to recognize and respect the traditional stewards of the land. It also reminds us of our responsibilities towards each other and towards addressing colonial structures. For help in crafting a meaningful land acknowledgement, please review the cited resources. 3,4

## Knowing and Preparing for your Audience:

It may be useful to let audience members know what themes are covered in the film. If the group has no prior knowledge of HIV, you may wish to provide an introduction to the topic (see <u>Background</u>). For service providers, a rich discussion may develop by inviting them to think about how the ideas shared in the film may impact their practice and care for women living with HIV. For people living with HIV, it may be helpful to inquire how to support their feelings or promote safety during the discussion, and ask them to reflect on how the themes from the film may resonate with or differ from their own experiences.

## Introducing Embodied Storytelling:

Preparing your audience to experience the use of embodied storytelling¹ can help them better engage with the film. The audio track of the film features the words of Juno Roche describing her experiences navigating pleasure and relationships as a woman living with HIV, while the video spotlights three performers who represent women living with HIV. Through embodied storytelling, the three performers enact the process of preparing for and meeting with a potential lover, disclosing their HIV status, and dealing with the emotions that follow. Embodied storytelling uses movement and dance to connect the viewer emotionally and physically to the story. It helps viewers feel experiences that are difficult to communicate through information and facts alone.

# **Background**

In this section, we provide background information about topics relevant to the film. You may wish to share this information before viewing the film or offer it as a resource during the discussion. In the appendices of this guide you will also find handouts that include a Language Check (Appendix E) and a Myth Check (Appendix E) that may be useful for audiences less familiar with HIV. For additional reading, please refer to the citations provided.

#### What is HIV?

- HIV stands for Human Immunodeficiency Virus (HIV) the immunodeficiency is the weakening of the immune system by the virus. 5
- If untreated, HIV can lead to Acquired Immunodeficiency Syndrome (AIDS) the name for a collection of illnesses caused by the virus. 5
- By taking medication called antiretrovirals (ARVs), people living with HIV are able to live long and healthy lives. 5
- In 2020, there were an estimated 37.6 million people living with HIV and approximatively 1.5 million new HIV diagnoses. About half of all people living with HIV are women.<sup>6</sup>

## *Undetectable = Untransmittable (U=U)*

- Medication reduces a person's viral load to undetectable levels, meaning someone can't pass on HIV to their sexual partners and their health is protected. 7-13
- For many people living with HIV, the U=U message is liberating, offering more agency over their sexual choices and also working to reduce HIV stigma. 14,15
- However, U=U is still not mainstream knowledge and improving awareness of U=U and the issues facing women living with HIV is essential towards reducing stigma and discrimination.<sup>16</sup>

#### Social <u>Stigma</u> and <u>Gender Inequity</u>

Gender inequity and violence intertwine to shape experiences of living with HIV. For women, violence and unequal power in negotiating safer consensual sex can increase the chance of HIV transmission and acquisition. 17 In addition, women living with HIV are targets of physical and sexual violence, as well as HIV-related stigma and discrimination. 18

- HIV- related stigma is multi-faceted and operates on multiple levels, including in individuals, and interpersonally, within organizations, society and policies.
   It can include rejection and harm from family, friends, and community but often expands to include discrimination from health care providers, making access to and maintenance of treatment more difficult.
- HIV-related stigma also manifests through discriminatory laws that criminalize
  unintentional transmission, exposure, and/or non-disclosure of HIV. A justification for
  these laws is to reduce the spread of HIV, but research shows they do the opposite,
  creating a culture of fear, violence, and persecution that create barriers for people living
  with HIV to access testing and treatment.<sup>21–24</sup>
- Women living with HIV are incredibly diverse and have diverse needs. The risks and consequences of HIV disproportionately affect underserved communities that already experience varying layers of systemic oppression, violence, and discrimination. Globally, this includes racialized women, adolescent girls and young women, transgender women, women who inject drugs, and women engaged in sex work with many intersections between these groups. 25-27
- Historically, women have been left out of the HIV narrative. This means that HIV advocacy, research, services, and funding for women living with HIV have been neglected, and women's distinct experiences and needs are often not acknowledged or met, particularly in relation to sexual health.<sup>28</sup>,<sup>29</sup>

### Sexual Health and Rights

- Sexual health is defined by the World Health Organisation as a state of physical, emotional, mental, and social well-being in relation to sexuality.  $\frac{30}{2}$
- Sexual rights are human rights. These include the right to control your own body, desires, experiences, and actions in relation to sexuality without discrimination, coercion, violence, or harm. They also include the right to positive and respectful relationships, pleasurable and safe sexual experiences, and overall sexual wellbeing.<sup>31-33</sup>
- Among women living with HIV, sexual health and rights are frequently overlooked and violated. Most discussions on sexual health centre on mitigating the risk of HIV transmission – painting women living with HIV as vectors of disease, rather than individuals deserving of sexual health, rights, desires, and pleasures.<sup>29,34-41</sup>
- We affirm the rights of women living with HIV to enjoy all aspects of life, including sexuality, on an equal basis to people without HIV. Women living with HIV deserve the best possible support in this area of their lives—support that respects their human dignity and worth.



## **Discussion Questions**

In this section, we provide suggestions of questions to promote dialogue for viewers to better engage with the film.

When considering which questions you will use, it is important to think about who your audience is and your goals for the film screening. Some questions are appropriate for all audiences, while others may be more suited to specific groups. Feel free to create your own questions and use whichever question(s) best suit your audience and goals.

## Pre-Screening Questions:

Before you screen the film, you may choose to ask some questions to introduce some of the topics and to invite your audience to reflect on their current knowledge.

- 1. Have you seen the film before?
- 2. On a scale from 1 to 5, with 5 being the highest: How would you rate your knowledge of HIV? How would you rate your knowledge of the issues facing women living with HIV? (You could also repeat this question at the end.)
- 3. Have you heard the term Undetectable=Untransmittable, or U=U?
- 4. Are you familiar with intersectionality?

## *Initial Reactions After Watching the Film:*

These questions can help the audience become comfortable conversing. They allow space for reflection on how each audience member connected to the film personally. Before asking about initial reactions, you may wish to give viewers a few moments after the film ends to sit with their thoughts and emotions.

- 1. How did watching the film make you feel?
- 2. While watching the film, what did you feel in your body?
- 3. What scenes or ideas stood out most to you from the film?
- 4. Did you learn anything about yourself while watching the film?



## Exploring themes:

These questions focus on themes explored in the film. They further contextualize the film and encourage deeper engagement. Below each question are some points to consider that are intended to guide viewers if they need additional prompts.

## 1. <u>Intersectionality</u> and <u>structural barriers</u>

Throughout the film, Juno emphasizes that women's and gender diverse people's experiences of U=U can vary greatly from men's experiences and are often unheard. What are some topics she discusses that might explain these differences? What things might impact how women experience U=U differently from each other?

**Points to consider:** History of the HIV/AIDS epidemic; patriarchy; gender-based violence; income inequity; racial discrimination; societal gender norms; differences in awareness of HIV among gay men versus other communities; differences in social identities and circumstances of women; gender and sexual norms.

## 2. Sex and bodily autonomy

One message that Juno highlights for women is, "You own your body. Whether that body contains HIV or not contains HIV, you own that body. You have every right to take risks, to not take risks. You have every right to all the same stuff that everybody else has, that men have." (6:46)

Do you feel like this sentiment is reflected in the norms of your culture? For people living with HIV, what interpersonal, cultural, or societal factors may impact their ability to express bodily <u>autonomy</u>, particularly regarding sex and pleasure?

**Points to consider:** Cultural mores regarding sex and sexuality, stigma, HIV non-<u>disclosure</u> laws; self-worth; self-love; power; validation; radical acceptance

#### 3. Disclosure

As the three performers show us the complicated emotional journey of meeting a potential sexual partner, Juno says, "And we know that a woman saying, 'I'm undetectable, trust me' in a face-to-face situation, it can be a risky thing." (3:23)

What possible dangers or complexities does this quote highlight in the choice to disclose one's HIV status? How does this complicate our understanding of U=U as a universally liberating message?

**Points to consider:** Intimate partner violence; HIV criminalization; social rejection; dating; stigma; vulnerability

## 4. Stigma

Juno highlights early in the film how U=U has helped dispel myths and fear surrounding HIV, as more people understand HIV as a manageable, chronic condition. But towards the end of the film she says, "Partially U=U is saying to people 'I'm clean! I'm clean! Be intimate with me, show me intimacy, I can't harm you." (8:10)

Considering this language, how might U=U play a complicated role in both destigmatization and re-stigmatization of HIV? What are the strengths and limitations of this campaign?

**Points to consider:** History of HIV/ AIDS; power dynamics; stigma; inequities accessing testing, treatment, and an undetectable HIV viral load; empowerment; human rights.

#### 5. Resilience

At the end of the film, Juno states "You know, HIV made me fabulous. HIV made me a fucking great writer. What has it done for you?" (8:20)

What is your response to this statement? What are some contributing factors towards the resilience of women living with HIV, both personal and societal? What role do you (as a healthcare worker, person living with HIV, researcher, policymaker, member of the general population, or other identity) have in supporting women's resilience and promoting respect, empowerment, hope, and health for women living with HIV?

**Points to consider:** Public education; legislation, health promotion, support groups, perspective shifting; community; advocacy; strength; empathy; celebrating one's body; perserverance; self-love; <u>allyship</u>; owning your identity

## Closing Thoughts

- 1. After watching and discussing the film, how have your beliefs, attitudes or understanding about living with HIV and the issues facing women changed?
- 2. How might the film and discussion move you to action or inspire change? (See <u>Further</u> Action)
- 3. To wrap up the screening, please share one word that describes how you are feeling after the film and discussion.



## **Further Action**



After sharing the film and engaging in the discussion, it is important to leave viewers with a call to action. Depending on who your audience is this might change – here are some ideas that you might consider sharing with your audience:

## 1. Reflect on your biases

After watching the film and participating in discussion, what have you learned? This film brings up complex topics that may challenge pre-existing ideas about what it is like to live with HIV as a woman. We invite you to reflect on the internal biases you may hold, and work to dismantle them.

## 2. Share HIV Made Me Fabulous with your network and encourage discussion

Host your own film screening and discussion with your colleagues, friends, and/or family! Take the time to discuss how the film made them feel, what they learned, and how it moves them to action. If you are screening in an HIV service setting, consider how the messages shared in the film might change your practice, care, or support for women living with HIV.

## 3. Support people who disclose their HIV status to you

<u>Disclosure</u> is a personal choice. If someone chooses to trust you with their HIV status, it is important to be supportive. <u>This HIV.gov resource</u> provides guidance on how to be supportive, but it is important to directly ask the person who discloses to you what kind of support that they would like.

## 4. Support organizations serving people living with and affected by HIV

Donate time or money to organizations in your community that work to fight stigma, improve care, and advocate for policy change that reflects the priorities of people living with HIV.

## 5. Participate in research

There are several studies that are actively recruiting people living with and not living with HIV, to better understand health, healthcare, and well-being. Please consider participating and contributing to progress our collective understanding about HIV globally.

## 6. Advocate for change

Structural change is necessary to make meaningful changes to improve the lives and wellbeing of women living with HIV. Consider writing to elected officials in your area to advocate for increased funding for woman-centered HIV initiatives, the decriminalization of HIV non-disclosure, or other sexual and reproductive health issues that you are passionate about. Also consider using your social media platform to help spread information to your network about the experiences of women living with HIV and important HIV science.



# **Additional Resources for Further Learning**

This section provides some additional resources where you can explore and learn more about a variety of topics related to this film. Consider sharing some of the resources here with your audience or adding your own!

- Visit <u>Life and Love with HIV</u> to read more from women living with HIV on their experiences of love, romance, and sexuality – including film narrator Juno Roche.
- To learn more about HIV & AIDS statistics around the world, visit UNAIDS. To learn more about the history of HIV/AIDS, view this timeline created by CATIE.
- For accurate, up-to-date information about all things HIV in general and from a Canadaspecific lens, visit **CATIE**.
- For more information about U=U, visit the <u>Prevention Access Campaign</u>. Read about some of the complexities of how U=U operates in the world in this piece by George M. lohnson: We Need to Talk About the Downside of U=U.
- The HIV Legal Network provides more information about the criminalization of HIV nondisclosure.
- Disclosure is a personal choice and an ongoing journey. To learn more about the process and get support, review Negotiating Disclosure: HIV Sero-status Disclosure Toolkit created by the Women's Health in Women's Hands Community Health Centre.
- The International Community of Women Living with HIV (ICW) is a network by and for women living with HIV. Explore either the **North America** or **Eastern Africa** branches for more information.
- The Global Network of People Living with HIV (GNP+) is another network for and run by people living with HIV. Visit their website to learn more about the advocacy work they do.
- To hear more from and connect with diverse people living with HIV, visit **POZ**. This platform includes news, personal blogs, and a social network among many other features.
- To learn more about research by, with, and for women living with HIV, explore the presentations and publications by the Canadian HIV Women's Sexual and Reproductive Health cohort study (CHIWOS) team and the British Columbia CARMA-CHIWOS Collaboration (BCC3) team.
- Looking for more? For additional books, websites, dating apps, and much more, visit the Resources section on Life and Love with HIV.

## References

- 1. Embodied storytelling [Internet], Edmond Kilpatrick, [cited 2021 Jun 15], Available from: https://www. edmondkilpatrick.com/embodied-storytelling
- Hammond W, Zimmerman R. A strengths-based perspective [Internet]. Resiliency Initiatives; 2012. Available from: https://www.esd.ca/Programs/Resiliency/Documents/RSL\_STRENGTH\_BASED\_PERSPECTIVE.pdf
- 3. Canadian Association of University Teachers. Guide to acknowledging First Peoples & traditional territory [Internet]. [cited 2021 Jul 23]. Available from: https://www.caut.ca/content/guide-acknowledging-first-peoplestraditional-territory
- Territory acknowledgement [Internet]. Native-Land.ca. [cited 2021 Jul 13]. Available from: https://native-land.ca/ resources/territory-acknowledgement/
- 5. HIV.gov. What are HIV and AIDS? [Internet]. 2020 [cited 2021 Jun 3]. Available from: https://www.hiv.gov/hivbasics/overview/about-hiv-and-aids/what-are-hiv-and-aids
- 6. UNAIDS. Global HIV & AIDS statistics fact sheet [Internet]. [cited 2021 Jun 14]. Available from: https://www. unaids.org/en/resources/fact-sheet
- Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S, van Lunzen J, et al. Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy. JAMA. 2016 Jul 12;316(2):171.
- Rodger AJ, Cambiano V, Bruun T, Vernazza P, Collins S, Degen O, et al. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. The Lancet. 2019 Jun 15;393(10189):2428-38.
- Castilla I, del Romero I, Hernando V, Marincovich B, García S, Rodríguez C. Effectiveness of highly active antiretroviral therapy in reducing heterosexual transmission of HIV. JAIDS J Acquir Immune Defic Syndr. 2005 Sep 1;40(1):96-101.
- 10. Bavinton BR, Pinto AN, Phanuphak N, Grinsztejn B, Prestage GP, Zablotska-Manos IB, et al. Viral suppression and HIV transmission in serodiscordant male couples: An international, prospective, observational, cohort study. Lancet HIV. 2018 Aug 1;5(8):e438-47.
- 11. Cohen MS, Chen YQ, McCauley M, Gamble T, Hosseinipour MC, Kumarasamy N, et al. Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med. 2011 Aug 11;365(6):493-505.
- 12. Prevention Access Campaign. Undetectable = Untransmittable [Internet]. Prevention Access Campaign. [cited 2021 Oct 14]. Available from: https://www.preventionaccess.org/undetectable
- 13. UNAIDS. Undetectable = untransmittable: Public health and HIV viral load suppression [Internet]. 2018 p. 4. Available from: https://www.unaids.org/sites/default/files/media asset/undetectable-untransmittable en.pdf
- 14. Persson A. 'The world has changed': Pharmaceutical citizenship and the reimagining of serodiscordant sexuality among couples with mixed HIV status in Australia. Sociol Health Illn. 2016;38(3):380-95.
- 15. Persson A, Ellard J, Newman CE. Bridging the HIV divide: Stigma, stories and serodiscordant sexuality in the biomedical age. Sex Cult. 2016 Jun;20(2):197-213.
- 16. Okoli C, Van de Velde N, Richman B, Allan B, Castellanos E, Young B, et al. Undetectable equals untransmittable (U = U): awareness and associations with health outcomes among people living with HIV in 25 countries. Sex Transm Infect. 2021 Feb;97(1):18-26.
- 17. Hankins C. Gender, sex, and HIV: how well are we addressing the imbalance? Curr Opin HIV AIDS. 2008 Jul;3(4):514-20.

- 18. Machtinger EL, Wilson TC, Haberer JE, Weiss DS. Psychological trauma and PTSD in HIV-positive women: a metaanalysis. AIDS Behav. 2012 Nov;16(8):2091-100.
- 19. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. Soc Sci Med. 2003 Jul 1;57(1):13-24.
- 20. Geter A, Herron AR, Sutton MY. HIV-Related Stigma by Healthcare Providers in the United States: A Systematic Review. AIDS Patient Care STDs. 2018 Oct;32(10):418-24.
- 21. Mykhalovskiy E. The public health implications of HIV criminalization: Past, current, and future research directions. Crit Public Health. 2015 Aug 8;25(4):373-85.
- 22. Patterson SE, Millov M-I, Ogilvie G, Greene S, Nicholson V, Vonn M, et al. The impact of criminalization of HIV non-disclosure on the healthcare engagement of women living with HIV in Canada: a comprehensive review of the evidence. J Int AIDS Soc. 2015 Dec 22;18(1):20572.
- 23. Barré-Sinoussi F, Karim SSA, Albert J, Bekker L-G, Beyrer C, Cahn P, et al. Expert consensus statement on the science of HIV in the context of criminal law. | Int AIDS Soc. 2018;21(7):e25161.
- 24. International Community of Women Living with HIV/AIDS. Criminalization of women living with HIV: Nondisclosure, exposure, and transmission. 2015.
- 25. Centers for Disease Control and Prevention. HIV by race/ethnicity [Internet]. HIV. 2019 [cited 2021 Jul 6]. Available from: <a href="https://www.cdc.gov/hiv/group/racialethnic/index.html">https://www.cdc.gov/hiv/group/racialethnic/index.html</a>
- 26. Public Health Agency of Canada. Population-specific HIV/AIDS status report: people living with HIV/AIDS. Ottawa; 2013.
- 27. UNAIDS. Women and HIV A spotlight on adolescent girls and young women [Internet]. UNAIDS; 2019 p. 20. Available from: <a href="https://www.unaids.org/sites/default/files/media\_asset/2019\_women-and-hiv\_en.pdf">https://www.unaids.org/sites/default/files/media\_asset/2019\_women-and-hiv\_en.pdf</a>
- 28. Bell E, Hale F, Kwardem L, Laycock D, Lennon J, Stevenson J. Women and HIV: Invisible no longer [Internet]. Sophia Forum and Terrence Higgins Trust; 2018 [cited 2021 Jul 9]. Available from: https://www.tht.org.uk/sites/ default/files/2018-08/women-and-HIV\_report\_final\_amended.pdf
- 29. Carter A, Greene S, Money D, Sanchez M, Webster K, Nicholson V, et al. The problematization of sexuality among women living with HIV and a new feminist approach for understanding and enhancing women's sexual lives. Sex Roles. 2017 Dec 1;77(11):779-800.
- 30. World Health Organization. Sexual health [Internet]. [cited 2021 Aug 13]. Available from: https://www.who.int/ westernpacific/health-topics/sexual-health
- 31. World Association for Sexual Health. Declaration of sexual rights [Internet]. 2014 [cited 2021 Jul 13]. Available from: <a href="https://worldsexualhealth.net/wp-content/uploads/2013/08/declaration\_of\_sexual\_rights\_sep03\_2014.pdf">https://worldsexualhealth.net/wp-content/uploads/2013/08/declaration\_of\_sexual\_rights\_sep03\_2014.pdf</a>
- 32. Logie CH. Sexual rights and sexual pleasure: Sustainable Development Goals and the omitted dimensions of the leave no one behind sexual health agenda. Glob Public Health. 2021 Jul 18;1–12.
- 33. Ford J, Corona Vargas E, Finotelli I Jr, Fortenberry J, Kismödi E, Philpott A, et al. Why pleasure matters: Its global relevance for sexual health, sexual rights and wellbeing. Int J Sex Health. 2019;31(3):217–30.
- 34. Carter A, Anam F, Sanchez M, Roche J, Wynne ST, Stash J, et al. Radical pleasure: Feminist digital storytelling by, with, and for women living with HIV. Arch Sex Behav. 2021 Jan 1;50(1):83-103.
- 35. Kaida A, Carter A, de Pokomandy A, Patterson S, Proulx-Boucher K, Nohpal A, et al. Sexual inactivity and sexual satisfaction among women living with HIV in Canada in the context of growing social, legal and public health surveillance. | Int AIDS Soc. 2015 Dec;18:20284.

- 36. Carter A, Greene S, Money D, Sanchez M, Webster K, Nicholson V, et al. Supporting the sexual rights of women living with HIV: A critical analysis of sexual satisfaction and pleasure across five relationship types. J Sex Res. 2018 Nov 22;55(9):1134–54.
- 37. Carter A, Greene S, Money D, Sanchez M, Webster K, Nicholson V, et al. Love with HIV: A latent class analysis of sexual and intimate relationship experiences among women living with HIV in Canada. Arch Sex Behav. 2019 May;48(4):1015–40.
- 38. Carter A, Patterson S, Kestler M, de Pokomandy A, Hankins C, Gormley B, et al. Sexual anxiety among women living with HIV in the era of antiretroviral treatment suppressing HIV transmission. Sex Res Soc Policy. 2020 Dec;17(4):765–79.
- 39. Patterson S, Carter A, Nicholson V, Webster K, Ding E, Kestler M, et al. Condomless sex among virally suppressed women with HIV with regular HIV-serodiscordant sexual partners in the era of treatment as prevention. J Acquir Immune Defic Syndr 1999. 2017 Dec 1;76(4):372–81.
- 40. Welbourn A. Desires denied: Sexual pleasure in the context of HIV. In: Jolly S, Cornwall A, Hawkins K, editors. Women, Sexuality and the Political Power of Pleasure [Internet]. London: Zed Books; 2013 [cited 2021 Oct 14]. p. 142–60. Available from: <a href="http://www.bloomsburycollections.com/book/women-sexuality-and-the-political-power-of-pleasure">http://www.bloomsburycollections.com/book/women-sexuality-and-the-political-power-of-pleasure</a>
- 41. Carlsson-Lalloo E, Rusner M, Mellgren Å, Berg M. Sexuality and Reproduction in HIV-Positive Women: A Meta-Synthesis. AIDS Patient Care STDs. 2016 Feb;30(2):56–69.
- 42. Bay-Cheng LY. Agency is everywhere, but agency is not enough: A conceptual analysis of young women's sexual agency. J Sex Res. 2019 Jun;56(4–5):462–74.
- 43. Sen G, Östlin P, George A. Unequal, unfair, ineffective and inefficient gender inequity in health: why it exists and how we change it [Internet]. Women and Gender Equity Knowledge Network; 2007 Sep. Available from: https://www.who.int/social\_determinants/resources/csdh\_media/wgekn\_final\_report\_07.pdf
- 44. Crenshaw K. Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. Univ Chic Leg Forum [Internet]. 2015 Dec 7;1989(1). Available from: https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8
- 45. Herrman H, Stewart DE, Diaz-Granados N, Berger EL, Jackson B, Yuen T. What is resilience? Can J Psychiatry. 2011 May 1;56(5):258–65.
- 46. Dulin AJ, Dale SK, Earnshaw VA, Fava JL, Mugavero MJ, Napravnik S, et al. Resilience and HIV: A review of the definition and study of resilience. AIDS Care. 2018 Aug;30(SUP5):S6–17.
- 47. Violence Prevention Alliance. Definition and typology of violence [Internet]. WHO. World Health Organization; [cited 2021 Aug 23]. Available from: <a href="https://www.who.int/violenceprevention/approach/definition/en/">https://www.who.int/violenceprevention/approach/definition/en/</a>

# **Appendices**

## ► APPENDIX A GLOSSARY

**Advocacy:** Speaking out and publicly supporting a cause with the intention of creating social change or influencing policy.

**Allyship:** The practice of advocating and supporting those within a group that you may not belong to. For example, someone not living with HIV may practice allyship with women living with HIV through many avenues, like educating their friends and family about HIV and U=U, and supporting organizations led by people living with HIV. There are many ways to be an ally, and it is an ongoing process not a destination.

**ARV:** Antiretrovirals, a medication that can be used to treat HIV.

**Agency:** The capacity of individuals to make purposeful choices and transform these into desired actions and outcomes within the social, cultural, economic, and political contexts specific to their daily lives. $\frac{42}{3}$ 

**Bodily autonomy:** Having bodily autonomy means that one is able to make decisions about their own body. As with agency, the ability for people to maintain autonomy over their own body is dependent on social, cultural, and political contexts.

**Disclosure:** The act of telling someone that you live with HIV.

**Discrimination:** The behaviours that result from stigma, can similarly operate on individual, interpersonal, and structural levels.

**Gender inequity:** Lack of consideration and response to the unique needs of each gender resulting in unequal outcomes between genders. 43

**Intersectionality:** This term, coined by Dr. Kimberlé Crenshaw, is used to describe how different aspects of one's identity (like race, class, gender) intersect to create unique lived experiences. These identities also exist in and overlap with larger social structures, which, together, impact on health outcomes.<sup>44</sup>

**Resilience:** The ability of a person or group to withstand adversity. Resilience results from interactions between personal factors (like personality traits and social relationships), biological factors (like changes in brain structure), and environmental-systemic factors (like social networks and relationships, community resources). 45,46

**Serostatus:** Whether a person is living with HIV or not. It refers to whether a person has antibodies that are specific to HIV.

**Stigma:** A multi-faceted process that operates on multiple levels, including within and between individuals. Stigma may result from in organizations, legislation, and policies and can systematically harm and exclude individuals based on membership in a certain group. 19

**Systemic oppression:** The disadvantaging of certain social groups compared to others, which is upheld and enforced by societal rules, policies, and institutions.

**Structural barriers:** The tools that enforce systemic oppression, like policies and laws, that disadvantaged certain social groups compared to others.

**U=U:** Undetectable equals untransmittable, a slogan used to convey the idea that when someone is on treatment and has an undetectable HIV viral load, they are unable to transmit HIV through condomless sex. 13

**Undetectable:** When someone with HIV has such a low level of the virus in their body that the medical tests used cannot detect it. This does not mean that someone is no longer living with HIV.

Violence: Intentional use of physical force or threats either against oneself or against others that can result in physical or psychological harm. Interpersonal violence (violence against others) can be physical, sexual, or psychological attacks, or neglect. 47

**Viral Load:** The amount of virus in a person's blood.

## ► APPENDIX B | SCREENING CHECKLIST

This shorthand checklist provides an outline for you to hold a screening. Make sure to refer to the main facilitation guide if you need more support in planning your screening.

### Before the Screening:

- Define your principles for safer spaces
- □ Familiarize yourself with a "strengths-based" approach
- Collect and learn more about local resources for audience members who may need further support
- Prepare your space (physical or virtual), including familiarizing yourself with the technology you will use to show the film

#### **Introductions:**

- □ Introduce yourself How did you come to this work?
- □ Territory acknowledgement Whose lands are you on?
- □ Prepare your audience Who are your viewers?\*
  - Provide necessary background on HIV, sexual and reproductive health, and your principles for safer spaces
  - Provide support resources
  - Provide overview of the film
  - Introduce embodied storytelling

#### Screen the Film:

- □ Ground everyone with a deep breath
- □ Screen the film
- Take a moment to absorb the film

#### Discussion:

- Remind participants to step away if they need and provide support resources
- □ Initial reactions *How did the film make viewers feel?*
- □ Exploring themes *Dig deeper into the complex issues presented in the film*
- □ Closing thoughts *What changes has the film inspired?*

### Wrapping Up:

- □ Issue a call to action
- Provide further resources
- □ Thank everyone
- Provide a space for film debrief, if needed

<sup>\*</sup>You may additionally choose to prepare participants with some pre-screening questions, also included in the guide

# ► APPENDIX C | CREATING SAFER SPACES — A GUIDING LIST OF PRINCIPLES FOR GATHERINGS BY ELDER VALERIE NICHOLSON

This document was created by Elder Valerie Nicholson, a key advisor for the creation of *HIV Made Me Fabulous* and its accompanying guide. These are some of the principles that she uses in creating a safer space when she is facilitating a group discussion:

**Respect** ~ yourself, others and the space, Mother Earth, our Rooted Family ~ the plants and trees, the winged ones, the finned ones, the four legged, the crawlers, and the waters the lifeblood of Mother Earth

**Wisdom** ~ everyone has wisdoms from their teachings that may differ from our own

**Courage** ~ challenge yourself, if you speak up a lot, let others speak; if you don't speak enough, speak up

**Honesty** ~ be honest with yourself

**Truth** ~ carry your own truths, and honour that my teachings maybe different from your teachings

**Humility** ~ ask for help if needed, and if you don't know, ask

**Love** ~ for Mother Earth ~ everything, everyone and self

What is learned here leaves here / what is said here stays here (Confidentiality)

**Talking stick** (sharing the air) one diva, one mike

"Don't Yuk my Yum" ~ For example, if I like candied salmon, don't go "ewww" and make me feel bad

**"Bodies will be bodies"** ~ move, stretch, stand, all bodies make noises, listen to your body's needs

# ► APPENDIX D SAMPLE AGENDA FOR A 90-MINUTE FILM SCREENING AND FACILITATED DISCUSSION

Although you can host a short screening where you introduce and screen the film with no discussion, we recommend having a longer screening where you and your viewers can take time to debrief and unpack the complexities of the film. Below is a sample 90-minute schedule that you can use or handout to viewers when screening the film.

Date:	Time:	Location:	
TIME	AGENDA ITEM		
5 mins	<ul> <li>Welcome: Facilitated by</li> <li>Facilitator introduction</li> <li>Territory acknowledgement</li> </ul>		
10 mins	View the film		
55 mins	<ul> <li>Discussing the film: Facilitated by</li> <li>Initial reactions (15 mins)</li> <li>Exploring themes (25 mins)</li> <li>Closing reflections (15 mins)</li> </ul>		
10 mins	Closing: Facilitated by  Call to action Further resources Thank you!		

# ► APPENDIX E | HANDOUT - LANGUAGE CHECK

It's important to be thoughtful about the language we use. Review this list of suggested phrasings to make sure the language you're using is accurate, inclusive, and non-stigmatizing. Keep in mind that language can change over time and in different contexts, so this is a guideline, not a set of rules. Entering conversations with humility and open-mindedness goes a long way. Finally, remember that when referring to others, it always comes down to what an individual would prefer you use.

Instead of	Try saying	Why?
HIV infected, HIV positive	Person living with HIV	Using person-first language centers the person you are talking about as an individual first and avoids defining them by their HIV diagnosis.
"Clean" (when referring to HIV serostatus)	Person not living with HIV, tested HIV negative	Using clean automatically implies that there is an opposite status - dirty. It stigmatizes and implies a value judgement.
Infection	Transmission	Infection carries a lot of stigma - there are connotations around being dangerous, dirty, or toxic. Using transmission is an accurate, less stigmatized term.
Victim	Person living with HIV	Person living with HIV is more accurate and centres humanity. Victim can imply defeat and helplessness.
Prostitute	Sex worker	Prostitution has a long, stigmatized cultural history. Sex work indicates agency and choice over career choice.
Transgendered or a transgender	Transgender, trans, transgender person, person of trans experience	Transgender is a descriptive word, rather than a noun. Using it as a noun is dehumanizing. Transgendered implies that the person was at one time not trans - which is inconsistent with the experiences of many people of trans experience.

#### Sources

BC Centre for Disease Control. (2020). BCCDC COVID-19 Language Guide: Guidelines for inclusive language for written and digital content. <a href="http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf">http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf</a>

Lynn, V., Watson, C., Giwa-Onaiwu, M., Ray, V., Gallagher, B., & Wojciechowicz, V. (n.d.). HIV #LanguageMatters: Addressing Stigma by Using Preferred Language. Retrieved July 29, 2021, from https://www.hiveonline.org/wp-content/uploads/2016/01/Anti-StigmaSign-Onletter-1.pdf

BCCFE Allyship Taskforce. (2020). BCCfE Inclusive Language Guide. Available by request allyship@bccfe.ca

# ► APPENDIX F | HANDOUT - MYTH CHECK

Myth check! Learn more about HIV by examining and debunking the following myths.

Myth	The truth
Only gay men have HIV	HIV does not discriminate. People from across the spectra of race, age, culture, religion, sexuality, and gender are living with HIV.
HIV can be transmitted through touching, hugging, kissing, or even being near a person living with HIV	HIV is not transmitted through saliva, touch, or the air. HIV is found in semen, pre-seminal fluid, rectal fluid, vaginal fluid, and breast milk. Transmission can occur in circumstances where these fluids enter a person's body through an open wound, injection, or a mucous membrane (skin that doesn't have as many protective layers, found in the rectum, vagina, and tip of the penis).
If I have sex with someone living with HIV, I will definitely test positive for HIV	There are many things that can impact the chances of HIV transmission. If the person living with HIV is on treatment and has an undetectable HIV viral load, there is no chance of transmission. Using a condom correctly also prevents transmission. Once the virus has entered your body, it is still possible for your immune system to fight it off before it becomes established. There are also drugs that can help your immune system in this process. You can take HIV antiretrovirals as either a preventative measure (PrEP) or after a possible exposure (PEP). Only if the virus is able to replicate and spread will transmission occur.
Women living with HIV should not be having sex	Women living with HIV have the same sexual rights as everyone else, including the right to have pleasurable, satisfying sex if they choose to.
Women living with HIV should take ARVs to protect others from HIV transmission	The main purpose of ARVs is to protect the health and wellbeing of the person living with HIV who is taking them. Women are more than just vectors of transmission and their own health is central to their care. It is an added benefit that treatment also prevents transmission.

#### Sources:

 $Arkell, C. \ (2021). \ Condoms \ for \ the \ prevention \ of \ HIV \ transmission. \ \underline{https://www.catie.ca/en/fact-sheets/prevention/condoms}$ 

Body Positive. (n.d.). HIV A New Diagnosis. Retrieved July 29, 2021, from https://www.bodypositive.org.nz/resources/PDFs/HIV\_A\_New\_Diagnosis.pdf Myths about HIV. (2019, February 22). The Well Project. https://www.thewellproject.org/hiv-information/myths-about-hiv

Wilton, J. (2011). From exposure to infection: The biology of HIV transmission. CATIE. https://www.catie.ca/en/pif/fall-2011/exposure-infection-biology-hiv-transmission

World Association for Sexual Health. (2014). Declaration of Sexual Rights. https://worldsexualhealth.net/wp-content/uploads/2013/08/declaration\_of\_sexual\_rights\_sep03\_2014.pdf