

Women and the International AIDS Conference: will anything change? An analysis of women living with HIV as abstract presenters at AIDS2016.



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Background

Women living with HIV and their organisations play a key role in generating and delivering evidence and research on what works for women, and should play a prominent role as speakers and oral presenters of research at International AIDS Conferences. This is in line with the new WHO Guideline on the Sexual and Reproductive Health and Rights (SRHR) of women living with HIV, which calls in Section 6.2.1 for women living with HIV as equal partners in researchⁱ; and with the increasing calls for meaningful community engagement to advance effective policies and programs in the context of HIV and SRHR^{ii,iii,iv}. In this light, we reviewed involvement of women living with HIV in presenting research at the AIDS2016 Conference.

Key Findings

- Women living with HIV had disturbingly few speaking opportunities at AIDS2016.
- Only 2% of women presenting at AIDS2016 self-identified as living with HIV.
- No abstracts submitted by transgender people were accepted for AIDS2016.
- Our search for gendered abstracts (co)authored by representatives of organisations of people living with HIV found: only 1 gendered abstract accepted for an oral abstract session; 2 were accepted for poster discussion sessions; and 9 were accepted for poster exhibition – women living with HIV were thus relegated to primarily non-speaking roles.
- Even when abstracts submitted by or with women living with HIV are accepted, women (including trans women) living with HIV may not be able to present their work due to lack of financial and/or scholarship support to attend International AIDS Conferences.

Methods

The AIDS2016 Abstract Book was searched for the terms ‘Women living with HIV’, ‘WLHIV’, ‘WLWH’. We then categorised by authorship the abstracts identified:

- (Co)authored by organisations of people living with HIV.
- Authored by academics/medical institutions, with no co-authors from organisations of people living with HIV.
- Authored by international agencies/NGOs/consultancies, with no co-authors from organisations of people living with HIV.

Additionally, we read all abstracts accepted for oral presentation sessions to ensure inclusion of those co-authored by an organisational representative of people (including women) living with HIV and relevant to women living with HIV, even if they did not contain our search terms.

We triangulated this with AIDS2016 data, provided to our team on request by the International AIDS Society (IAS), on women and transgender presenters and speakers living with HIV. Inquiries were also made about the number of scholarships awarded to trans people for the AIDS2018 conference and how this compared to previous conferences.

Results

45 abstracts for AIDS2016 contained our keywords, and of these the following were (co)authored by an organisational representative of people living with HIV:
 Poster Exhibition: 9; Poster Discussion: 2; Oral Abstract: 1. (See Table 1)

The review of all oral abstracts for AIDS2016 revealed 4 additional abstracts (co)authored by an organisational representative of people living with HIV including women living with HIV. None of these was explicitly gendered or women-focused.

Table 1: Key term search of AIDS2016 Abstract Book

Number of abstracts found using search terms Women living with HIV, WLHIV, WLHA	Authored by academic/medical institutions only	Authored by national/local NGO, international NGO or UN organisation	(Co)authored by an organisation of people living with HIV			
			Total	Poster Exhibition (9)	Poster Discussion (2)	Oral Abstract (1)
45	21	12	12	TUPED272 TUPED277 TUPED299 TUPED383 WEPED345 WEPED415 WEPED454 WEPED502 THPED307	TUPDD0306 WEPED0202	WEAD0303

Data provided by the IAS for AIDS2016 showed only 2% of women presenters self-identified as living with HIV. 142 self-identified HIV positive women had submitted abstracts. Of these, 21 (15%) abstracts were selected, 120 (85%) were rejected, 1 (<1%) accepted but withdrawn. All 17 abstracts submitted by self-identified positive trans people were rejected (100%). Of 137 invited women speakers, 15 (11%) identified as living with HIV. (See Table 2)

Table 2: Data obtained on request from IAS about women presenters living with HIV at AIDS2016

Description	Number
AIDS2016 Presenters (includes presenters of Oral Abstracts, Poster Discussions, Poster Exhibitions)	
Women presenters	1048 (54% of all presenters)
Women presenters who self-identified as living with HIV	21 (2% of women presenters)
Transgender presenters	14 (1% of all presenters)
Transgender presenters who self-identified as living with HIV	0
Abstract submission and acceptance figures	
Self-identified women living with HIV who submitted abstracts	142 (of which 20 submitted more than 1 abstract)
Abstracts by self-identified women living with HIV approved	21 (15% approval rate)
Abstracts by self-identified women living with HIV approved but withdrawn	1 (<1%)
Abstracts submitted by self-identified women living with HIV rejected	120 (85% rejection rate)
Abstracts submitted by self-identified trans people living with HIV	17
Abstracts submitted by self-identified trans people living with HIV approved	0
Abstracts submitted by self-identified trans people living with HIV rejected	17 (100% rejection rate)
Invited speakers	
Invited women speakers	137
Invited women speakers self-identified as living with HIV	15 (11%)
Invited transgender speakers	8
Invited transgender speakers self-identified as living with HIV	1

AIDS 2018 scholarships awarded to trans applicants

At AIDS2016, no abstracts submitted by transgender people were accepted. However, according to information about scholarships provided to our team by the International AIDS Society, ‘We are happy to report that while not as substantial as we’d like, there is some progress each year. This year we were able to support more than 1,100 people – an unprecedented number of scholarships for any AIDS conference. Transgender people, as other key and vulnerable populations, are at the core of the scholarship programme. We are encouraged that this year’s scholarship programme received the highest number of applications from transgender people (176 applicants identified as transgender, +16% compared to AIDS 2016 and +57% compared to AIDS 2012). The acceptance rate for trans applicants is 4% higher than the overall acceptance rate for scholarship applications, which means we are supporting more transgender people than for any previous AIDS conferences. However, even though the number of scholarship applicants identifying as transgender is increasing, it still represents only 2% of our applications, and we would like to see more.’

This means that 29 scholarships were awarded to self-identifying trans applicants. We do not have figures on how many of these applicants identify as living with HIV.

Since the scholarship review process, Global Action for Trans Equality has been accepted as a Conference Coordinating Committee member, and we hope this will mean continuing increases in the success rates for trans scholarship applications, and abstracts (co)authored by trans people, as well as more trans representation in speaking and presenting roles at future conferences.

Observations and limitations

- A search for ‘living with HIV’ in the abstract book produces 665 results – far more than our searches for ‘WLHIV’ (11 results), ‘WLHA’ (6 results) or ‘women living with HIV’ (86 results). This indicates a significant lack of gender disaggregation within abstracts.
- The search terms chosen are indicative rather than exhaustive. We did not include the terms ‘female’, ‘HIV-infected women’, or ‘HIV-positive women’ (which tend to be used in more medical or academic spheres). We also decided not to use key population-specific search terms which are not gendered such as ‘trans’, ‘sex worker’, ‘drug user’.
- The identification of organisations of people living with HIV was conducted manually. It is not always clear from the name whether a listed affiliation is an organisation of people living with HIV, so there may be cases when relevant (co)authored abstracts have been missed.
- In some cases, abstracts (co)authored by organisations of people living with HIV (including women representatives of these organisations) contain no gender disaggregation or specific mention of women. As a result, these did not appear in our search.

Discussion

The lack of opportunities for women living with HIV to present their work in oral sessions at the International AIDS Conference is deeply at odds with more recent research which calls for the urgent need for community involvement in SRHR/HIV linkages and in policy and program development at all stages. There is much room for improvement in numbers of scholarships for women (including trans women), and for more women living with HIV (including trans women) as (co)authors of abstracts selected – especially for oral presentations.

There is a marked and urgent need to develop clear regulations regarding meaningful involvement of women living with HIV in all their diversity in research, in peer-review journal articles and at conferences, as oral presenters. **This is both an intrinsic right and is also of key importance to advance effective policies and programs in the context of HIV and SRHR.** Scholarship schemes must support women (including trans women) living with HIV to enable them to attend and present their work.

Future Plans

We plan to compare these findings with final data regarding representation of and speaking opportunities for all women living with HIV, including trans women, at AIDS2018. This will support the future improved involvement of women living with HIV in abstract-driven sessions and through the scholarship programme at AIDS2020 and beyond.

i World Health Organization. Consolidated guideline on sexual and reproductive health and rights of women living with HIV. Geneva: WHO, 2017. Available at: <http://apps.who.int/iris/bitstream/handle/10665/254885/9789241549998-eng.pdf;jsessionid=69F64EC2BCD40706D233889A8F73FD20?sequence=1> (accessed July 2018).
 ii Salamander Trust, Athena, UNAIDS, AIDS Legal Network, Project Empower, HEARD, University of KwaZulu-Natal. ALIV(H)E (Action Linking Initiatives on Violence Against Women and HIV Everywhere) framework. 2017. Available at: http://salamandertrust.net/wp-content/uploads/2017/11/ALIVHE_FrameworkFINAL_Nov2017.pdf (accessed June 2018).
 iii Orza L, Bass E, Bell E, Crone ET, Damji N, Dilmitis S, Tremlett L, Aidarus N, Stevenson J, Bensaïd S, Kenkem C. In Women’s Eyes: Key Barriers to Women’s Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being. Health and human rights. 2017 Dec;19(2):155.
 iv Hale, F., Bell, E., Banda, A., Kwagala, B., van der Merwe, L.L.A., Petretti, S., Yuvaraj, A. Keeping our core values ALIV[H]E. Holistic, community-led, participatory and rights-based approaches to addressing the links between violence against women and girls, and HIV. Journal of Virus Eradication, 2018, 4. Available at: [http://viruseradication.com/journal-details/Keeping_our_core_values_ALIV\[H\]E_Holistic_community-led_participatory_and_rights-based_approaches_to_addressing_the_links_between_violence_against_women_and_girls_and_HIV/](http://viruseradication.com/journal-details/Keeping_our_core_values_ALIV[H]E_Holistic_community-led_participatory_and_rights-based_approaches_to_addressing_the_links_between_violence_against_women_and_girls_and_HIV/) (Accessed July 2018).

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