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Transgender HIV research: nothing about us without us

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We are trans scientists, health-care providers, and advocates, and we were in the room along with a dozen of our peers at the panel *Perspectives of transgender women on HIV prevention and care* at the International AIDS Society conference (IAS) on July 22, 2019. With 5 min remaining for the question and answer period, we lined up at the microphone. We found ourselves facing a panel of four cisgender researchers (one of whom misgendered a colleague while presenting) and one transgender woman, a Spanish-speaking therapist who was asked to share her personal life story—without simultaneous translation. The irony was not lost on us that each presenter spoke of socioeconomic exclusion and a shortage of professional opportunities as structural drivers of HIV risk and incidence among trans people, in a session excluding trans people from a professional opportunity.

Indeed, trans people face stigma and discrimination globally, with severely limited access to formal education and the labour market.^{1,2} We were pleased to hear that some of the projects presented had included capacity-building initiatives for trans staff and community members. And, we categorically reject the notion that there do not already exist trans people in all

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countries who are capable of presenting scientific research. Trans researchers, whether trained in academia or in community settings, exist in all corners of the world. Trans authors were leads of all the publications cited in this Comment.

The session encapsulated the scientific and ethical problems that permeate transgender research presented at scientific meetings, funded by governments and donors, and published in leading journals. Trans populations are increasingly the focus of HIV science, after three decades of advocacy by trans women challenging their neglect in the global HIV response. Our positions as researchers and scientists, however, are undermined when our methodological and substantive expertise is undervalued (eg, relegated to peer recruiter roles) or made invisible (eg, by inviting cisgender researchers to speak on our behalf).

Taking the IAS programme as an example, we can identify scientific problems that could have been avoided by marshalling the expertise of trans researchers and advocates. Responding to calls for disaggregation of transgender women in studies of men who have sex with men, abstract titles increasingly refer to men who have sex with men and transgender women. Such inclusion is often only nominal; at the 2019 IAS meeting, 51 abstracts mentioned transgender people in the title. Of these, only 34 disaggregated data for transgender participants from cisgender participants or were exclusively about transgender people. Further, transgender status does not constitute a behavioural risk for HIV. Trans people can be lesbian, gay, bisexual, queer, asexual, or heterosexual;³ a substantial number of trans women are at little risk of HIV because they are sexually inactive or sexually active with cisgender women, whereas a large number of trans men are at risk of HIV, because they are sexually active with cisgender men.⁴ Yet, only six abstracts at IAS 2019 specified the risk group to which transgender study participants belonged. We found only three abstracts that specifically mentioned transgender men or non-binary people.

For future IAS meetings, we propose several remedies. We call on researchers to include transgender women, men, and non-binary people, who are at risk of or living with HIV in their research. Existing guidelines on inclusive data collection should be adapted to local contexts with the involvement of trans people.^{5,6} Additionally, data from trans participants should be disaggregated, including reporting the number of transgender women, men, and non-binary participants in abstracts that mention them. We also encourage authors to be clear and focused in describing the population at risk (eg, specifying transgender women who have sex with men).

Cisgender researchers receiving funding for research with trans populations have an ethical obligation to address the power imbalances that contribute to their receipt of such funding in the first place. Cisgender researchers should ask about the gender composition of transgender health panels that they are invited to speak on and should decline invitations to participate in panels when trans researchers are not equitably represented. For both abstract-driven and invited sessions, cisgender researchers should promote the leadership of trans coresearchers, including dedicating funds for travel and securing translation, if necessary. Sitting in the audience or appearing in photos in a slide deck does not constitute meaningful involvement of trans colleagues. When presenting on transgender health research, we

encourage proactive disclosure of the involvement of trans people (or absence thereof) in all stages of the research.

IAS and other organisations could take various concrete actions to promote trans scientific leadership at their meetings. IAS proudly announced that half of abstract presenters at this year's meeting were women. How many were transgender people? At present, the IAS registration form only permits self-identification as male, female, or transgender, despite scientific and community consensus that this is inappropriate and fails to capture many trans people who identify as men or women.^{5,6} We recommend that IAS modify the registration form to reflect best practice, and then regularly report data on the number of abstracts presented by transgender women and men and by non-binary people. Abstract submitters could also be asked to describe the involvement of affected populations in research design and implementation. To promote participation of trans researchers, key population members should be prioritised in scholarship decisions, alongside (and intersecting with) people living with HIV. IAS could also include trans people among the many invited speakers for plenaries, special sessions, and symposia, as well as guarantee trans representation on the scientific committee. Finally, IAS should ensure that trans people are safe and respected at their meetings by providing gender-neutral washroom facilities for those who need them and by proactively avoiding misgendering (eg, active promotion of pronoun stickers for name badges and advance briefing of translators and session moderators). We look forward to collaborating with IAS and with our cisgender allies in the HIV research community to implement these changes.

References

1. Restar AJ, Operario D. The missing trans women of science, medicine, and global health. *Lancet* 2019; 393: 506–08. [PubMed: 30739673]
2. Reisner SL, Poteat T, Keatley JA, et al. Global health burden and needs of transgender populations: a review. *Lancet* 2016; 388: 412–36. [PubMed: 27323919]
3. James SE, Herman JL, Rankin S, Keisling M, Mottet L, Anafi M. The report of the 2015 US transgender survey. Washington, DC: National Center for Transgender Equality, 2016 <https://www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF> (accessed Aug 12, 2019).
4. Scheim AI, Bauer GR, Travers R. HIV-related sexual risk among transgender men who are gay, bisexual, or have sex with men. *JAIDS* 2017; 74: e89–96. [PubMed: 27798432]
5. The GenIUSS Group. Best practices for asking questions to identify transgender and other gender minority respondents on population-based surveys. Los Angeles, CA: The Williams Institute, 2014 <https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-reportsep-2014.pdf> (accessed Aug 12, 2019).
6. International Reference Group on Transgender People and HIV/AIDS. Counting trans people in: advancing global data collection on transgender communities and HIV. Oakland, CA: IRGT, 2016 <https://transglobalactivism.org/wp-content/uploads/2016/07/Counting-TransPeople-In-Web.pdf> (accessed Aug 12, 2019).