

GLOBAL HEALTH RESEARCH AMONG TRANSGENDER POPULATIONS: CONSIDERATIONS AND APPROACHES

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Outline

- **Considerations**
 - Cultural humility & power imbalances
 - Current issues in global health research among trans populations
- **Research methods**
 - Including the community perspective
 - Methods for enrolling stigmatized populations
- **Example: my research**

Considerations: Cultural humility and power imbalances

Cultural humility: a construct to approaching global health research

Dimensions of cultural humility:

- Lifelong learning and critical self reflection
- Recognize and challenge power imbalances
- Develop partnerships that advocate for others

Acknowledge what you don't know

- Include **voices** and **knowledge** from the community
- Do **research that is needed** by the community, not just to serve intellectual curiosity
- **Learn** from the community and **adapt** your research plan to address their needs
- Due diligence to **understand the cultural and historical background**, not just the disease/health

Important for both research integrity and ethics

Recognize and address power imbalances

“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.”

THE LANCET HIV

COMMENT | VOLUME 6, ISSUE 9, PE566-E567, SEPTEMBER 01, 2019

Transgender HIV research: nothing about us without us

Ayden I Scheim  • Max Nicolai Appenroth • S Wilson Beckham • Zil Goldstein • Mauro Cabral Grinspan • JoAnne G Keatley • et al. [Show all authors](#)

Published: August 19, 2019 • DOI: [https://doi.org/10.1016/S2352-3018\(19\)30269-3](https://doi.org/10.1016/S2352-3018(19)30269-3)

How?

- Partner with trans investigators
- Engage trans community throughout your research process
- Promote leadership and mentoring of trans scientists
- Ensure your trans collaborators receive authorship

Considerations: Current issues in global trans health research

Problem 1. Trans women often conflated with men who have sex with men (MSM)

Too small of sample size  excluded from analyses
analyses not stratified by gender



Hakim et al. BMC Public Health (2019) 19:623
<https://doi.org/10.1186/s12889-019-6942-7>

BM  AIDS Care
Psychological and Socio-medical Aspects of AIDS/HIV

AIDS and Behavior
<https://doi.org/10.1007/s10461-019-02492-x>

RESEARCH ARTICLE

ORIGINAL PAPER

HIV Prevention Method Preferences Within Sexual Partnerships Reported by HIV-Negative MSM and TW in Tijuana, Mexico

H. A. Pines¹ · R. Patrick¹ · D. M. Smith¹ · A. Harvey-Vera¹ · J. S. Blumenthal¹ · G. Rangel² · S. J. Semple³ · T. L. Patterson³

Why we... syphilis among men, and transgender v... with men, Bangkok, Thailand, 2005-201...

TH Holtz^{1,2}, W Wimonstate¹, PA Mock¹, S Pattanasin¹, W Sukwicha¹, ME Curlin^{1,2}, A Chitwarakorn³, and EF Dunne^{1,2}

among cisgender men who have sex with men and transgender women in Eswatini: a latent class analysis

Open Access

CrossMark

Conflation of MSM and trans women

Conflation due to:

- Common anatomy and mode of transmission (anal sex)
- Trans women difficult to engage in research
- Failure to capture appropriate gender in surveillance
- Lack of understanding of gender vs sex assigned at birth

Result:

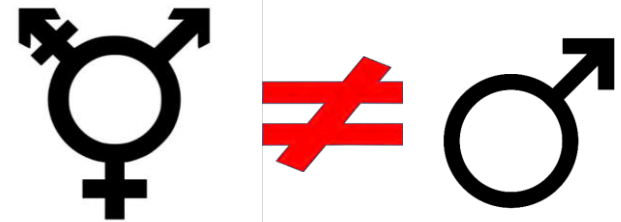
Lack of data among trans women



Worse outcomes and uptake of interventions

What can we do?

- Conduct research tailored to trans populations
- If targeting both trans populations and other gender groups:
 - Use recruitment strategies and language that directly target trans populations
 - Plan your power and recruitment based on subgroups
 - Track recruitment of subgroups and adjust recruitment if needed
 - Disaggregate results for analysis and reporting



Problem 2. Sexual and gender identity not appropriately captured

- Sexual orientation and gender identity lumped into single descriptor
- Gender assessed through a single yes/no question
- Fail to include a range of gender identification options
 - “Transgender woman” or “transgender man” doesn’t represent everyone
 - Gender non-conforming or non-binary persons not represented in most research

Gender and sexual orientation not uniformly defined

- Culture-specific language around gender identities and sexual behavior
- Language to describe gender and sexual orientation might be rooted in deeper historic or cultural meaning



<https://transglobalactivism.org/wp-content/uploads/2016/07/Counting-Trans-People-In-Web.pdf>

Problem 2. Sexual and gender identity not appropriately captured

Example: HIV study in Peru

- Only asks about current gender identity, no information on sex assigned at birth
- Not all trans women identify using this language
- Combined gender and sexuality: if they said yes to 11, question 12 was skipped
 - *Not appropriate in US context, but appropriate in Peru?*

11.- ¿Se considera una travesti/transgénero/transexual?[*] [179BBAK]

Marque sólo una opción.

No ₀ Si ₁

12.- ¿Cómo te consideras respecto a tu sexualidad?[*] [179BBAL]

Marque sólo una opción.

Homosexual ₀ Bisexual ₁ Heterosexual ₂

What can we do?

Example of two-step ascertainment as used by the Public Health Seattle King County STD Clinic:

Two-step Ascertainment

<p>Section Header: <i>Gender Information</i></p> <p>What is your gender?</p>	<p>radio, Required</p> <table border="1"> <tr><td>0</td><td>Male</td></tr> <tr><td>2</td><td>Female</td></tr> <tr><td>3</td><td>Transgender Woman/Transfeminine</td></tr> <tr><td>4</td><td>Transgender Man/Transmasculine</td></tr> <tr><td>5</td><td>Non-binary/Genderqueer</td></tr> <tr><td>6</td><td>Not listed, please specify</td></tr> </table>	0	Male	2	Female	3	Transgender Woman/Transfeminine	4	Transgender Man/Transmasculine	5	Non-binary/Genderqueer	6	Not listed, please specify
0	Male												
2	Female												
3	Transgender Woman/Transfeminine												
4	Transgender Man/Transmasculine												
5	Non-binary/Genderqueer												
6	Not listed, please specify												
<p>Please specify gender <i>(Write in response)</i></p>	<p>text, Required Field Annotation: @CHARLIMIT=30</p>												
<p>What sex was recorded on your original birth certificate?</p>	<p>radio, Required</p> <table border="1"> <tr><td>0</td><td>Male</td></tr> <tr><td>2</td><td>Female</td></tr> </table>	0	Male	2	Female								
0	Male												
2	Female												
<p>Which pronouns do you use?</p>	<p>radio</p> <table border="1"> <tr><td>1</td><td>He/him</td></tr> <tr><td>2</td><td>She/her</td></tr> <tr><td>3</td><td>They/them</td></tr> <tr><td>4</td><td>Not listed, please specify</td></tr> </table>	1	He/him	2	She/her	3	They/them	4	Not listed, please specify				
1	He/him												
2	She/her												
3	They/them												
4	Not listed, please specify												

Tordoff 2018

What can we do?

Existing guidelines on inclusive data collection should be **adapted to local context** with the **involvement of trans people**

Scheim 2019



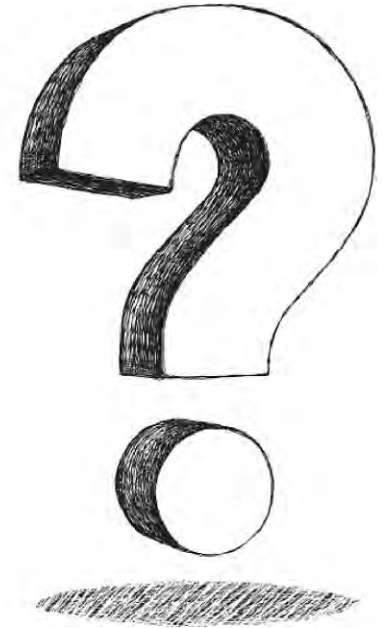
**BEST PRACTICES FOR ASKING QUESTIONS
TO IDENTIFY TRANSGENDER AND OTHER
GENDER MINORITY RESPONDENTS ON
POPULATION-BASED SURVEYS**

Created by the Gender Identity in U.S. Surveillance (GenIUSS) group, a multi-disciplinary and multi-institutional collaboration

<https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>

Problem 4. Not enough research asking the right questions

- Research among trans women not targeted to them
- Trans masculine populations vastly underrepresented in research
- Research among trans populations heavily focused on HIV and “gender transition”, not well represented in other health topics



Problem 4. Not enough research asking the right questions

Example: iPrEx

- Lacked targeted recruitment of trans women
- Poor language to indicate gender identity
- Mis-gendered participants, did not stratify in original reporting
- Did not properly address issues important to trans populations
 - Drug-drug interaction of PrEP with feminizing hormones
 - Gender-affirming care

Transgender Women in Clinical Trials of Pre-Exposure Prophylaxis

Grant, Robert M. MD, MPH; Sevelius, Jae M. PhD; Guanira, Juan V. MD; Aguilar, Jana Villayzan MPH; Chariyalertsak, Suwat MD, DrPH; Deutsch, Madeline B. MD, MPH

JAIDS Journal of Acquired Immune Deficiency Syndromes: August 15, 2016 - Volume 72 - Issue - p S226–S229
doi: 10.1097/QAI.0000000000001090

What can we do?

- Conduct research tailored to trans populations
- Include trans populations, including trans men, in research of other health issues
- Include trans researchers:
 - Invite a trans researcher to collaborate as PI, contribute to planning and preparation
 - Involve a trans health consultant: <https://www.transhealthconsulting.com/>
 - Include trans staff in implementation

Research Methods: Including community Perspective

Need input on a wide range of study aspects

- How to reach the community
- What the community wants
- Incentives for them to join research
- Barriers to joining research
- Language that is appropriate, understood, and means the same thing you think it means
- The role of stigma, discrimination, and legal persecution: differs widely

Involvement of trans community

- Key informant interviews
- Trans investigators
- Trans study staff
- Community advisory boards
- Member check (informant feedback, respondent validation)
- Focus groups



Qualitative aim within study

- Focus groups → groups of participants
- In-depth interviews → individual participants

Why?

- Inherent bias in ways we collect data and interpret outcomes
- Provide depth and context to quantitative data
- Can discover things you didn't know to ask

Research methods: Enrolling stigmatized populations

Methods developed for hard to reach populations

Often, stigmatized populations can't be reached through random population sampling

- Small populations
- Difficult to find and/or engage in research
- Distrust of researchers due to oppression/discrimination

Alternative methods of data collection:

- Venue based/Time-space sampling
- Snowball sampling
- Respondent-driven sampling

Piloting your study

- Pilot your study in your key population
 - Identify issues with implementation
 - Areas of confusion in questionnaires
 - Assess willingness of participation

Other tips:

- Trust building between communities and researchers takes time; work within existing networks
 - Can volunteer or attend community events
- Adapt to needs to participants
 - Choose study locations that cater to the community
 - Consider online research or other methods to protect identity in places where stigma/discrimination is a consideration

Practical Applications: My Research

Background

- HIV is not a generalized epidemic in Peru: <1% overall prevalence
- But, there are epidemics in subgroups
 - 12-18% prevalence among MSM
 - 29-39% prevalence among trans women
- Little is known about the sexual partners of trans women

Objective: To characterize the partners of trans women

Community support and buy in

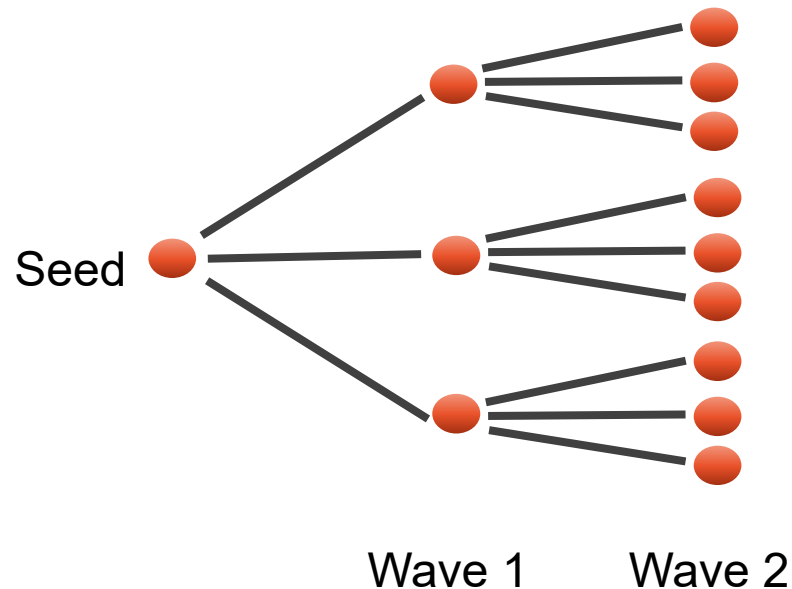
- **Worked with organizations** that were well integrated with community
 - Epicentro and Impacta: NGOs working with trans women
 - The Feminas House: a social support center for trans women
- **Key informant interviews**
 - Spoke with community members, activists, other researchers, health care providers
- **Focus groups with target populations**
 - Separate groups that are key to study such as trans women, sexual partners
- **Pilot testing**
 - Both informal and formal piloting

Incorporating lessons:

- Hired staff from the target community
- Changed the language we used around gender identity
- Modified recruitment methods
- Changed payment process and study hours to better serve our population
- Added links and information about HIV testing

Method to reach population: Respondent-driven sampling

- Begin with seed participant
- Each recruits 3 social contacts
- Each of those recruits can recruit 3 contacts
- Branch out in “waves” of participants through the social network



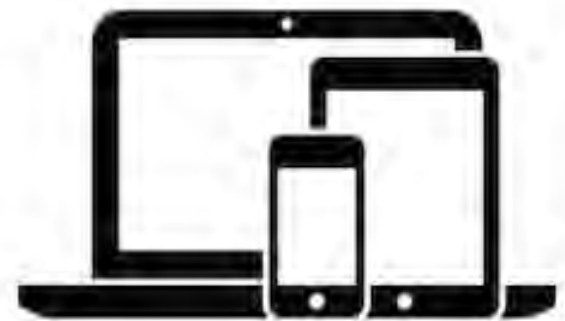
Assumption that with enough waves, you move away from the bias in the seed selection and have a sample that is representative of the population

Adapting to community needs: Online data collection

Traditional RDS: conducted in-person at a study site

Modification: online data collection to protect privacy

- “Anonymous” online survey
- Available on any device with internet access
- Collected phone numbers for reimbursement and forward recruitment
- Allowed for recruitment via WhatsApp



Dissemination and sustainability

- Disseminated results to Impacta, Epicentro, and Feminas
- Drafted new grant proposal to translate findings to improvements in HIV testing and care delivery
- Publish: more published research focused on trans communities specifically is needed!
 - Include trans collaborators and staff in my publications

Thanks!

More information about my research:

CROI poster: <http://www.croiconference.org/sessions/little-or-no-overlap-sexual-networks-transgender-women-and-msm-lima-peru>

Contact me:

jesslong@uw.edu

