



Case Study: IRB Challenges in International HIV Research Involving Women Engaged in Sex Work

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Thank you to RETI Institute Members

- Yuko, E., Goldenberg, S., & Urada, L. (in preparation). The impact of criminal, immigration and health care laws and policies on the human rights and welfare of sex workers: Case studies across diverse global settings.
- Goldenberg, S., Rivera Mindt, M., Rocha Jimenez, T., Brouwer, K. C., Morales, M., & Fisher, C. B. (2015). Structural and interpersonal benefits and risks of participation in HIV research: perspectives of female sex workers in Guatemala. *Ethics & Behavior*. 25(2). DOI: 10.1080/10508422.2014.950270
- Urada, L. A. & Simmons, J. (2014). Social and Structural Constraints on Disclosure and Informed Consent for HIV Survey Research Involving Female Sex Workers and Their Bar Managers in the Philippines. *Journal of Empirical Research on Human Research Ethics*: 9, 29-40.

Background: Tecún Umán

- Guatemala has high rates of HIV and barriers to care among key populations including women engaged in sex work (FSW).
- Situated along the main entryway from Central America into Mexico, the community of Tecún Umán hosts a thriving sex industry in venues such as bars, parks, plazas, hotels, and truck stops.
- Whereas sex work remains criminalized in Guatemala, it is regulated by public health officials in certain municipalities – including Tecún Umán – which require FSWs to register and receive periodic HIV/STI testing at municipal clinics.

Legal & Safety Risks for FSWs

- Sex work is tolerated in Tecún Umán for women who work in formal establishments such as nightclubs and carry a “sanitary control card” indicating they have been HIV/STI tested
- However, FSWs in non-bar based settings often work without permits and are harassed or extorted by local police.
- Tecún Umán is also characterized by frequent undocumented border crossings, and is known as a source, destination, and transit country for forced sex work and trafficking.
- FSWs in this region are often victims of violence - Guatemala has one of the highest murder rates in the world, and violence is common along the northern border with Mexico.

Purpose & Significance of Study

- The research team proposed a mixed method study of migration, sex work, and sexual health among FSWs along the Mexico-Guatemala border in Tecún Umán.
- The study was designed to address the critical need for research to understand and inform interventions to address the HIV/STI-related vulnerabilities faced by FSWs in this region.

Study Aims

To determine the extent to which HIV infections and willingness to undergo periodic HIV/STI testing among FSWs are related to:

- Work venue (e.g. formal establishments or street work)
- Immigration status (local versus migrant or trafficked women)
- Attitudes of brothel managers toward regulated HIV/STI testing
- Risk factors including use of condoms, injection drug use, and forced sex work.
- FSWs' concerns regarding the legal, economic and social consequences of testing positive for HIV/STI

Recruitment & Interviews

Recruitment would be conducted through:

- Managers at local establishments
- A partnership with RedTraSex, a Latin American sex worker advocacy group run by former and current sex workers
- Street recruitment
- Respondent driven sampling.

Community workers drawn from RedTraSex would recruit and conduct interviews in “safe spaces” rented in areas frequented by and convenient to FSWs.

IRB Concerns: Legal

- While accepted in some areas, sex work is illegal in Tecún Umán
- Failure to comply with HIV/STI testing and to carry a sanitary control card is illegal and carries fines
- FSWs who are in the country illegally can be arrested and deported
- Victims of trafficking also face prison for being an illegal migrant; they may be held for long periods of time since the jurisdiction for illegal trafficking is often uncertain among countries
- Trafficked women are often asked to testify against the traffickers as a means of avoiding prison
- Punishment for drug use is imprisonment of 4 months – 2 years

IRB Concerns: Informational Risk

- Recruitment or data collection methods may lead to Identification and arrest or extortion by police if sex work, failure to possess a sanitary control card, or drug use is exposed
- Recruitment efforts may alert managers or traffickers to the women's research participation risking punitive actions
- Arrest or the attention of government officials may lead to deportation or forced testimony against traffickers
- Revealing the HIV/STI positive status of women may result in loss of jobs or punishment by managers, traffickers, or family members

IRB Questions: Recruitment

- Will RedTraEx community workers be less likely to attract attention from law enforcement? To be more trusted by women? Are they sufficiently trained to ensure that contact does not attract attention?
- Should managers who may have positive relationships with RedTraEx or who are amenable to the study be used as gatekeepers?
- Will not involving the managers lead to poorer recruitment or negative consequences for employees who chose to participate?
- If so, although investigators will maintain confidentiality of interview results, will managers demand from FSWs a report on the interview?

IRB Concerns: Coercion

- Managers may coerce FSWs who work for them to participate
- Offering monetary compensation may be “coercive” if women perceive they can be harmed by participation
- If participants are compensated for their participation managers may demand a portion of the compensation
- It is not uncommon for RDS “informants” in drug using populations to demand a fee from participants

IRB Questions: Informed Consent

- Should consent should oral (no signature required) to avoid a means of participant identification? If so, how will consent be documented?
- What “risks” should be listed in the consent?
- Is a Certificate of Confidentiality of any value? Is discussing it disingenuous?

IRB Questions: Interviews

- Should the interviews be conducted by community workers or trained investigators? What is the risk community workers would blur their research and advocacy roles?
- What type of screening and training would be necessary to ensure community workers adhered to scientific and ethical standards of interviewing?
- What are the informational risks of audio recording interviews (necessary for validity if community workers are conducting the interviews)?
- What are the validity concerns and informational risks of limiting data to interviewer written notes?

IRB Questions: Compensation & Coercion

- Should FSWs be paid? Will they use money to buy drugs? What is a fair payment? Should food coupons be used instead?
- Should RDS be used? If so, how will the PI protect participants against extortion? Should they? Or is this business as usual?
- Should managers be paid for their willingness to permit their employees to participate? Would that be considered contributing to an illegal establishment?
- Should the advocacy group be paid for their partnership?