

The 29th Annual Canadian Conference on HIV/AIDS Research Le 29e Congrès annuel canadien de recherche sur le VIH/sida

Session: **SS2**: Friday May 1 - 15:00:17:00 - Engaging (with) Communities in HIV Research

Track: Social Sciences
Subject: Engaging (with) Communities in HIV Research
Presentation Type: Oral
Title of Abstract: **“People give and take a lot in order to participate in things:”
Making a Case for Non-Participation in HIV CBPR and participatory
programming with young people**
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Abstract

Background: Common typologies used in community-based participatory health research and programming¹⁻³ frame participation as existing at different hierarchical levels. Scholars have critiqued these typologies for ignoring contextual specificities and the complexities, nuances, and power dynamics inherent in participatory processes^{4,5}. Non-participation is positioned as something negative, or not addressed at all. **Methods:** In this study, we used photovoice (a method where participants are given cameras to identify, document and analyze issues in their communities) to understand how stakeholders (n=11) at a youth-led, HIV prevention and harm reduction peer education project understood 'youth engagement'. In response, participants told us about the challenges of participating in youth-led programming and research. Drawing on Tuck's⁶ desire-based framework, I provide a visual and thematic analysis of how youth understood and navigated this 'call to participation' in complex, and self-determined ways. **Results:** Participants shared: what it meant to "act engaged", the hidden costs of participating (including burn-out), and the importance of trust when navigating the 'choice' to participate. Participants' voices bolster the work of critical scholars who have questioned the discursive role of participation in enacting neoliberal strategies of surveillance and control - in other words, what is at stake when young people are invited to *willingly* participate in processes that may appear voluntary. Drawing on Indigenous theorists who advocate for a politics of refusal^{7,8}, I argue that young people's refusal to participate (or to participate on their own terms) may be an act of resistance - especially for youth whose bodies are regulated on a daily basis. **Implications:** Young people are savvy and well-aware of how participation functions in participatory HIV research and programming. In these contexts, non-participation may be considered a form of refusal. Practitioners are wise to consider the possibilities that non-participation engenders.