

Lessons Learned from Respondent-Driven Sampling Implementation: Trans PULSE

Greta Bauer,* Michelle Boyce ,
Todd Coleman, Nooshin Khobzi,
Robb Travers, Jake Pyne, Kyle
Scanlon, for the Trans PULSE
Project Team

Presentation:

19th Annual Canadian Conference on
HIV/AIDS Research
Oral Presentation
Saskatoon, SK, Canada
May 2010



* Epidemiology & Biostatistics, University of Western Ontario

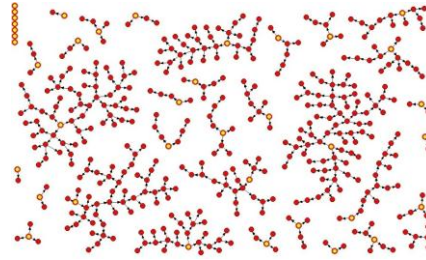


- Community-based study of how social exclusion impacts the health and HIV vulnerability of trans people in Ontario.
 - Trans is defined broadly, and may include those who identify as transgender, transsexual, two-spirit trans, transitioned, bigender, genderqueer, or simply man or woman.
- Trans people constitute a 'hidden population' that experiences high levels of social exclusion.
- Desire for rigorous methods for producing population estimates, so results would stand up to scrutiny



What is RDS?

- Systematic method of chain-referral sampling
- Recruitment networks and network sizes are tracked
- Bias is addressed through recruitment strategies and statistical analysis



What makes this study unique among RDS studies?

- Province-wide Ontario study (non-local)
 - Little or no prescribed contact between research team and participants beyond initial seeds
- Level of community involvement
- Trans communities
- Multi-mode survey
 - Online, paper, telephone (interpreters available)



Strategy: Survey and recruitment

- 87-page survey
- Friendly and personal
- Anonymity possible
- Recruitment quota=3
- Seeds=16 initially



Strategy: The technical side of things

- Developing and piloting = the biggest time delay
- Custom programming required to implement RDS. Adobe LiveCycle survey was embedded in original programming.
- Required time-consuming and frustrating pilot testing. Community Engagement Team members were champs!



Strategy: Non-local RDS survey promotion

- Methods we used:
 - Talking to everyone possible
 - Posters
 - Postcards
 - Press
 - YouTube
 - Facebook
 - Listserv postings
 - Public events
 - Meetings and calls with community leaders



What we learned: Participants as agents

- Participants strategized around distribution of tickets
 - Giving two to well-connected people to ensure recruitment goes on, one to someone who would not be reached otherwise
 - Distribution by mail to those who are not online
 - Strategic participant efforts to reach those living on First Nations Reserve communities, in rural areas, and in prisons
 - Reaching out via listservs, Facebook groups, FetLife, the Men's Room, and other electronic communities
 - YouTube videos by participants
 - Nearing deadline, "code dumps" online
 - Community members actively seeking tickets

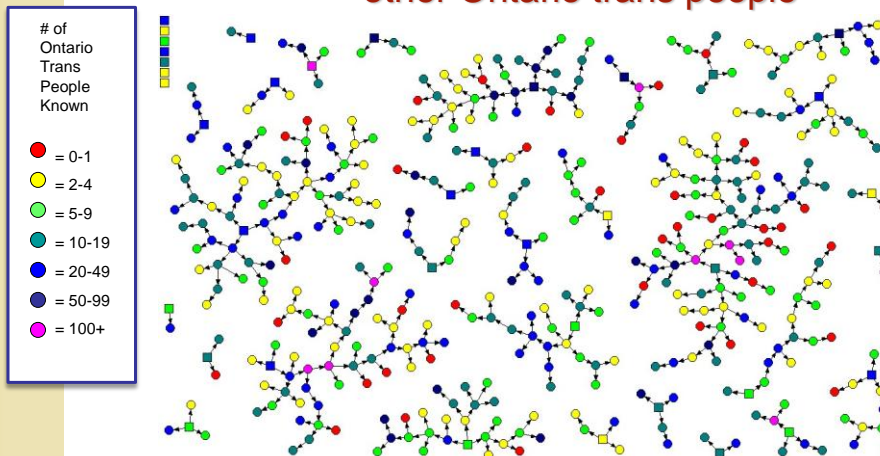


What we learned: High levels of participant motivation

- 433 participants for an 87-page survey
- 51% collected \$20 honorarium, 31% donated to a trans-related community group, and 18% provided no information
- Phone calls from individuals wanting to participate
- Addition of secondary incentives in final two months had an unknown effect



What we learned: Participants' connectedness to other Ontario trans people



Recruitment Trees, n=432 participants



Challenges

- No clear way to set number of initial seeds or recruitment quotas
- Promotion messaging: on one side "This is great. Do it and tell your friends," on the other, "Wait till you get a ticket"
- Language issues: "3 of your friends" vs. "3 people you know"
- Third-party honorarium system was cumbersome



Challenges

- Concerns over inclusion of underrepresented groups led some participants to circumvent the RDS process
- Some feelings of exclusion from those who wanted to participate
 - "I understand the motivation for having this survey passed from friends to friends, though ... this has led people to feel excluded and have (potentially very triggering) anxiety about not fitting in, not being 'trans enough', in general not being 'popular' enough to get a survey."

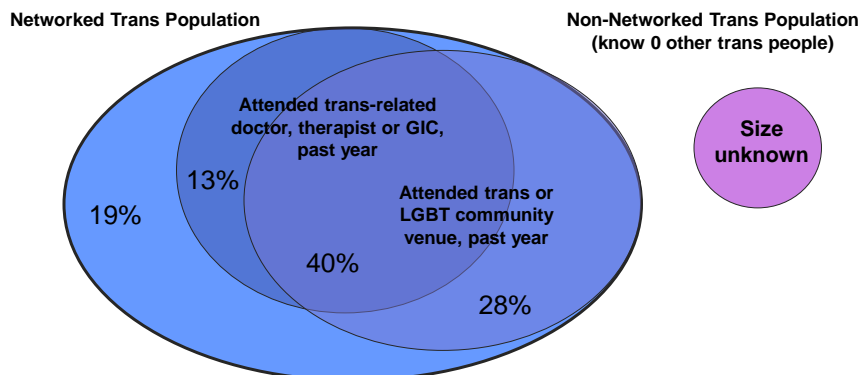


Evaluating our success

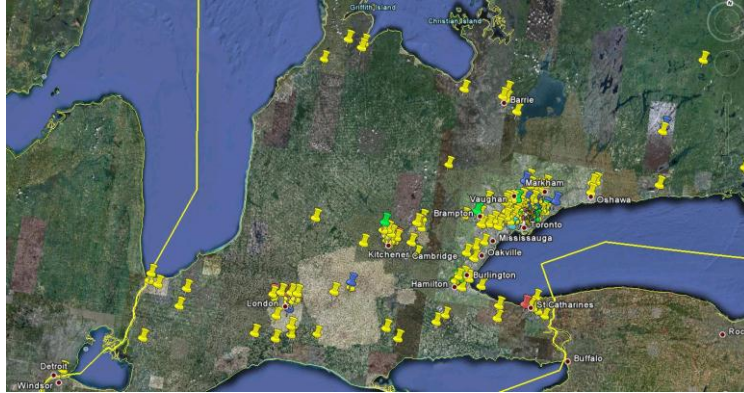
- 433 participants
 - Less than goals, but higher proportion of population than in recently completed large U.S. internet studies
 - Immense wealth of information with high policy relevance
- Overwhelmingly positive responses from most participants
 - Gratitude for participation and for our work, felt they had learned from the survey, optimistic about what would be done with results
- Some community members felt frustrated or excluded
- Can generate meaningful statistics for trans communities



Potential population accessibility through venue-based sampling



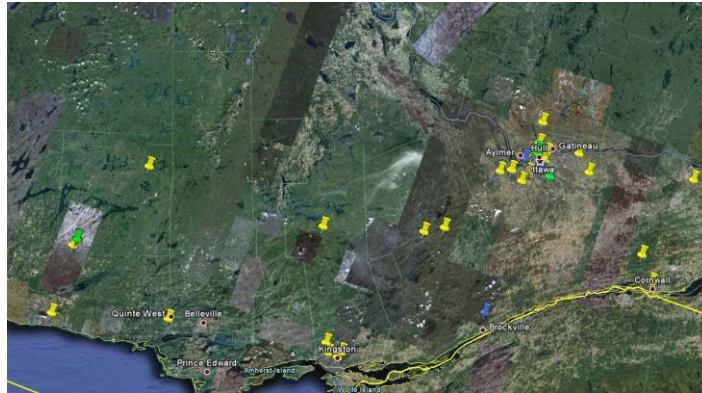
Southwestern Ontario



TransPULSE



Southeastern Ontario



TransPULSE



Northern Ontario



TransPULSE



Keys to making it work

- Communication with participants beyond initial seeds is crucial
- Education of community leaders provides a consistent message, and stimulates promotion
- Detailed understanding of the community is required
 - Community leadership
 - Language and knowledge of concerns and needs
 - Community faith that something will be done with results
 - Presence within communities, online and at events
- Technical resources
 - Web-based strategies, toll-free phone line

TransPULSE



Trans PULSE Team

Investigators

Greta Bauer
Robb Travers
Michelle Boyce
Rebecca Hammond
Anjali K
Matthias Kaay
Nik Redman
Kyle Scanlon
Kenji Tokawa
Anna Travers

Project Staff

Todd Coleman
Jake Pyne

Funders



Community Engagement Team

Nael Bhanji
J.R. Caughlin
Starr Daniels
Adrian Edgar
Elizabeth James
Anjali K
Michelle Le-Claire
Matt Lundie
Teanor Mahood-Greer
Devi McCallion
Mason McColl
Caleb Nault
Evana Ortigoza
Catherine Purdie
Tyson Purdy-Smith
Will Rowe

Graduate Students

Nooshin Khobzi
Andrew Warner
Roxanne Longman
Brodan Giambrone
Karin Hohenadel
Scott Anderson
Melisa Dickey

Other Contributors

Rupert Raj
Sydney Tam
Yasmin Persad
Brady Yu

433 Participants!



Trans PULSE

**We know transphobia is bad for our health
we need your help to prove it.**

Trans PULSE is asking 1000 trans people in Ontario to tell us their stories. This spring, trans people across Ontario will invite each other one-by-one to participate in this project. If you identify as trans and you live in Ontario, you may get asked to fill out a survey in the near future. You will likely be asked by another trans person that you know and after completing it, you will be able to invite three others. Your information will be used to change the way health care and services are provided to trans people across Ontario.



The Trans PULSE survey is different than other surveys – everyone must wait to be asked to fill it out. Trans people will invite each other to participate one-by-one until we reach 1000. Using this method will produce results that are more accurate and ensure we have the maximum impact possible. Trans PULSE is not simply collecting information – we are trans people, allies and researchers who are committed to action.

This survey is mostly check-boxes and can be filled out on-line or with paper and pencil in approximately 60 minutes. Language interpreters are available; all information is confidential, and everyone receives an honorarium for participating. If you identify as trans or as a person of trans history, we want to hear from you. We hope you will consider sharing your unique experiences and helping us prove that discrimination is bad for our health.

For more info: 1 877 54 PULSE or info@transpulse.ca
www.transpulse.ca

Building our communities through research



Contact information

info@transpulseproject.ca
<http://www.transpulseproject.ca>

greta.bauer@schulich.uwo.ca

