

HHS Public Access

Author manuscript *AIDS Behav.* Author manuscript; available in PMC 2017 June 01.

Published in final edited form as:

AIDS Behav. 2016 June ; 20(6): 1265–1274. doi:10.1007/s10461-015-1234-4.

A Web 2.0 and Epidemiology Mash-Up: Using respondent-driven sampling in combination with social network site recruitment to reach young transwomen

Sean Arayasirikul^{1,2}, Yea-Hung Chen¹, Harry Jin, and Erin Wilson^{1,3}

¹Center for Public Health Research, San Francisco Department of Public Health, San Francisco, CA, United States

²Medical Sociology, Department of Social and Behavioral Sciences, University of California San Francisco, San Francisco, CA, United States

³Department of Epidemiology and Biostatistics, University of California San Francisco, San Francisco, CA, United States

Abstract

Respondent-driven sampling (RDS) peer referral has been proven to be an effective recruitment method for hard-to-reach populations; however, its application in diverse populations is limited. Recruitment occurred in two phases: RDS-only followed by development and implementation of an online social network strategy in combination with RDS peer referral (RDS+SNS). Compared to RDS-only, RDS+SNS reached a sample that was younger ($\chi^2=9.19$, P=.03), more likely to identify with a non-binary gender identity ($\chi^2=10.4247$, P=.03), with less housing instability (50.5% vs. 68.6%, $\chi^2=9.0038$, P=.002) and less sex work (19.7% vs. 31.4%, $\chi^2=5.0798$, P=.02). Additionally, we describe lessons learned as a result of implementing our online social network strategy. Our findings underscore the importance of integrating Internet-driven strategies to meet challenges in sample diversity and recruitment of young transwomen.

Keywords

transgender; young adults; Internet; recruitment

INTRODUCTION

Advances in online social networking have been driven by significant web 2.0 technologies and have changed the way society interacts and forms social ties. There are recent efforts to adapt social networking sites into public health research for recruitment and retention (1-3). Because research has shown that youth are the heaviest users of the Internet (4) and the Internet has an important role in the identity development of LGBT youth (5), the Internet may be an efficacious method in recruiting LGBT youth as a hard-to-reach population in

Corresponding Author: Sean Arayasirikul, PhD(c), Center for Public Health Research, San Francisco Department of Public Health, 25 Van Ness Ave, Floor 5, San Francisco, CA 94102, United States, Phone: 415-554-9036, Fax: 415-431-7547, Sean.Arayasirikul@ucsf.edu.

public health research. Literature on the online recruitment of persons at risk for HIV acquisition have focused on gay and bisexual men (6, 7) and not transwomen, even though HIV rates among transwomen have been shown to surpass all other behavioral risk groups (8).

Transwomen, or individuals assigned male sex at birth who identify as a gender other than male, have a 34 times greater odds of HIV infection than the general population (9). Though rates of new HIV infection have appeared to level off and in some risk groups have decreased (10), high rates of HIV infection continue to persist among transwomen (11). Transwomen of color face greater HIV rates compared to their white counterparts (12-14). Research explaining the causal pathways of HIV infection among transwomen is scant; though transwomen have exhibited higher rates of sex work in response to the marginalization, institutional discrimination and transphobia they face in society (15).

Respondent-driven sampling (RDS) has been proven to be an effective methodology to sample and recruit hard-to-reach hidden populations. RDS employs a dual incentive, peer referral system by paying participants for completing the survey as well as for assisting in recruiting additional participants to help ensure successful recruitment (16). This process begins with enrolling a set of seeds, which broadly represent the target population in regards to general demographic characteristics, to complete the study. They, in turn, recruit their peers from their social networks into the study, beginning the peer referral recruitment chains. RDS has been successfully implemented to recruit samples of female sex workers (17), intravenous drug users (18-20), adult transwomen (13, 21-23) and other vulnerable populations (24, 25) difficult to sample due to the stigma they face in society. However, RDS has also been shown to be unsuccessful in some populations (26, 27).

The parent study described in this paper sought to recruit a large, diverse longitudinal cohort of young transwomen using RDS and to characterize HIV risk and resilience factors in this population. The purpose of this analysis is to describe the peer referral networks of young transwomen recruited in this study and to assess how the demographic make-up of the sample changed as a result of incorporating an online social network strategy. We also discuss lessons learned as a result of implementing an online social network strategy.

METHODS

Institutional Review Board Review

All study procedures were approved by the IRB at the University of California, San Francisco. Written consent was obtained from all youths aged 18 years or older and written assent was given by younger participants (in accordance with a review board waiver of parental consent).

Eligibility and Procedures

This study is a longitudinal HIV risk and resilience study among young transwomen in the San Francisco Bay Area. Participants eligible for this study met the following criteria: be between 16 to 24 years old; live in the San Francisco Bay Area; be either English or

Spanish-speaking; self-identify as a transwoman, individuals born assigned male sex at birth and currently identifies as any gender other than male; and able to provide informed consent.

Standard procedures for RDS were implemented (16). Working with community-based organizations and community leaders, 10 seeds were identified and enrolled in the study. Each seed, or sociometric star, received with 3-5 coupons to refer their peers to the study. Each subsequent peer referred participant eligible to participate in the study were given 3-5 coupons to refer eligible peers. Baseline data collection activities were conducted in-person with research staff. After screening for eligibility and obtaining informed consent, research staff administered a computer assisted behavioral survey and conducted an HIV antibody test (The Clearview® HIV 1/2 STATPAK ®, Alere, Waltham, MA, USA). Participants were paid an incentive of \$50 for completing their baseline data collection activities and \$20 per successful referral of a peer to the study.

The decision to develop and implement an online social network strategy in conjunction with RDS was influenced by the prolonged period of time (approximately 9 months) having elapsed without reaching a sample size with sufficient statistical power. Before deciding to incorporate an online social networking strategy with RDS, a number of modifications to RDS methodology were made to address enrollment challenges. First, we offered productive seeds the option of additional coupons beyond the 3-5 coupons initially provided to them. Second, after communicating with seeds about the status and lack of successful referrals, we added 5-10 additional seeds per month to the mix. One important factor that influenced this change in methodology was the limitation of a longitudinal study where baseline assessments needed to be completed by a certain point in the grant period in order to allow time for the completion of follow-up assessments.

Data Analysis

We present descriptive sociometric and network data for all participants using Graphviz (28). To assess the impact of the online social network strategy, we conducted Chi-square tests to analyze and compare demographic characteristics of participants recruited during the first phase of study recruitment – RDS only (time 1) – and after we implemented our online social network strategy with RDS or RDS+SNS (time 2). Data analyses were completed with SAS (version 9.3) (29). Basic demographic characteristics assessed were age, gender, race/ethnicity, education, religion, employment history, monthly income, history of housing instability, and history of sex work.

RESULTS

Enrollment and Peer Referral Network Data

During the first nine months of RDS-only recruitment, we enrolled an average of 2-3 participants a week (see Figure 1). After implementing our online social network strategy, weekly enrollments increased to 4-5 participants a week. In total, recruitment during RDS-only yielded 79 participants in a nine month period and online social networking in combination with RDS produced 221 participants in twelve months.

The mean number of peers participants reported knowing in the San Francisco Bay Area was 7.14 (Table I). The mean number of peers participants would be willing to provide a referral coupon to was 5.46. Homophily was assessed on a scale of -1 (participant recruited only from outside their group) to 1 (participant recruited only from inside their group). Coefficient values at either extreme were not observed among the variables of race/ethnicity and gender identity. Hispanic and trans-identified participants had a moderate positive homophily (approximately 0.3), suggesting a moderate tendency to recruit others of the same race/ethnicity or gender identity. Black and Asian participants had a stronger positive homophily (approximately 0.5 and 0.4, respectively) suggesting a greater tendency to recruit others of the same race/ethnicity. Mixed participants were neither homophilous nor heterophilous. Figure 2 is a visualization of sequential peer referral chains for the overall sample. Nine seeds were productive with two or more waves. The most productive seed was provided with 6 coupons, which resulted in four waves and a total of 12 recruits.

Demographic Differences by Type of Recruitment

Table II describes the demographic characteristics of the overall sample and differences stratified by recruitment period wherein Time 1 is comprised of RDS-only and Time 2 of RDS in combination with an online social network strategy (RDS+SNS). Forty-four percent of participants identified as female and a third as transwomen. The largest racial group in this sample was white (35.7%). Most of the sample had completed high school or had some college education (33.7% and 35.0%, respectively), and reported a monthly income of \$0 to \$500 (52.2%) and a history of unstable housing (56.7%). Almost a quarter of the sample (23.7%) reported having had engaged in sex work in the past.

When stratified by recruitment time period, RDS+SNS (time 2) yielded a more diverse sample along a number of demographic characteristics compared to RDS-only (time 1). Compared to RDS-only, RDS+SNS generated participants who were younger ($\chi^2=9.19$, P=. 03), and more likely to identify with a non-binary gender identity ($\chi^2=10.4247$, P=.03). Non-binary gender identities occupy spaces outside the man-woman binary and include such identities as agender, gender as object (e.g. identifying as a unicorn or mermaid), gender queer or third gender. Additionally, RDS+SNS recruited participants with less history of housing instability (50.5% vs. 68.6%, $\chi^2=9.0038$, P=.002) and sex work (19.7% vs. 31.4%, $\chi^2=5.0798$, P=.02) compared to RDS-only (time 1).

DISCUSSION

Our study results identified differences in the composition of young transwomen recruited by RDS-only and in combination with an online social network strategy (RDS+SNS). Participants recruited by RDS-only were older, financially insecure, marginally housed, experienced with sex work, and trans- or female-identified compared to those recruited during RDS+SNS. Participants recruited by RDS-only appear to represent a different demographic profile than those recruited during RDS+SNS. The diversity that RDS+SNS contributed to this study is in line with recent developments on how to best sample populations of transwomen (30, 31). Bauer and Scheim published their concern over selection bias in studies of transwomen reported in Baral et al.'s systematic review and

meta-analysis which found a pooled HIV prevalence of 19.1% worldwide (9, 31). In response to Bauer and Scheim, Baral et al. explained, "sampling strategies that are most pragmatic in most settings tend to oversample high risk transgender women," subsequently calling for improved sampling strategies (30). Integrating online social network strategies like RDS+SNS may introduce important diversity in samples of transwomen. In particular, obtaining a sample of younger transwomen who have yet to enter a phase of HIV risk taking is crucial in developing interventions for this population.

Contingent on how well individuals were able to recruit their peers, RDS assumed that the hidden population be connected with each other within a defined geographic location (26). Consequently, weak social ties have shown to be a barrier for successful RDS implementation. Simic's work using RDS to recruit sex workers in Serbia and Montenegro proved challenging because of the hidden nature of and weak social ties among sex workers (27). Recent data suggested that young transwomen struggle with social isolation (32), or chose to strategically time and manage their coming out process and identity as transwomen, which has impacted their relationship to transgender peers. These factors may have explained some of the recruitment challenges of RDS-only in comparison to RDS in combination with our online social networking sampling strategy.

Methodological developments in RDS studies have expanded to include the use of web adaptations of RDS, referred to as webRDS, which may help to address these challenges (26, 33). WebRDS uses an online Internet portal to assign unique identifiers to participants and enable them to generate electronic coupons and linked email messages which can be sent to peer referrals (26). Few studies have utilized webRDS (33-37), and none have been applied to young transgender populations. However, there is evidence that webRDS may be advantageous for hidden youth populations for whom research participation may be stigmatizing (38). Racial, gender, and sexual minorities are especially vulnerable to medical mistrust, fear of authority, stigma, mistreatment, and exploitation (39-42). HIV research studies have struggled to sample adolescents due to HIV-related perceived stigma and negative social consequences (38). WebRDS may address these issues and make research more accessible and youth-friendly (33). WebRDS has been found to address some of these challenges around communicating with potential peer referrals by affording youth the ability to recruit peers through passive or active strategies, using the approach that they prefer most (33). WebRDS may alleviate specific factors relevant to young transwomen such as social anxiety related to recruiting peers, possibly assisting in protection of their gender identity (33). Though we did not utilize webRDS, more robust sampling via the internet is should be considered for future studies with this important population.

Limitations

This analysis had several limitations. Since there was a paucity of information about peer referral networks of young transwomen in the San Francisco Bay Area, we were unable to determine if this study recruited a representative sample of young transwomen. Though RDS sampling has its limitations, deviating from RDS by implementing an online social network strategy may have impacted the results to an even greater extent. Studies that rely on RDS for recruitment use statistical corrections to adjust for recruitment biases introduced by the

method; however, these statistical corrections cannot be used due to the methodological change.

The number of individuals approached during RDS+SNS was not documented. As a result, we are unable to characterize the response rate of potentially eligible participants. We also did not collect data to make comparisons between RDS as a whole and an internet-based sample. Additionally, recruitment methods that relied on how young transwomen constructed online identities (e.g. user profiles, etc.) may over-select young transwomen who are more comfortable being out as transwomen to their online social networks.

How to determine when RDS has failed is less discussed in the scientific literature. RDS is theoretically designed to resolve attrition problems related to linear recruitment chains by allowing seeds to produce multiple referrals, avoiding any one single seed's failure to produce referrals from stopping the sampling process (43). Failure to produce ample referrals during the first nine months warned study staff of potential RDS failure. If given unlimited time and financial resources, recruitment chains may have propagated. This is an important challenge for research settings especially within the context of a longitudinal study where time and resources are limited and making methodological decisions midcourse as a result will impact future applicability of these data. Specifically, deviating from RDS in the current study results in the inability to derive RDS population estimates and compensate for non-random recruitment.

Consulting other RDS studies, youth populations in general have proven to be a group particularly difficult to recruit using RDS (33, 44-47). One study, for example, required 12 waves of recruitment to achieve a sample size of 259 young women with multiple sex partners in South Africa (44). In a recent U.S. study, it took over three years to recruit a sample of 450 young men who have sex with men (YMSM) (45). While the parameters for determining RDS failure may be unclear, successful implementation of RDS among adult transwomen is clear. The TEACH (Transfemale Education to Advance Community Health) Study has been successfully implemented using RDS with recruitment lasting a 3 month period in 2010 and 2013 (13, 48, 49). While these limitations diminish the generalizability of our study's results, this is the first large longitudinal sample of young transwomen and a critical opportunity to gain insight in the various recruitment methods necessary to reach this population in order and understand the social and health needs of this population.

Lessons Learned

Social Networking Sampling Strategy and Procedures—We developed a targeted online social network strategy that consisted of four important steps: 1) identifying social network site platforms with a presence of young transwomen as users, 2) optimizing search functionality, 3) developing platform-specific content and 4) leveraging the social context of Facebook. These steps helped to identify an online sampling frame specific to young transwomen. Research staff messaged every transwoman that may be eligible for the study by gauging interest, followed by eligibility screening. Eligible participants were consented in-person by staff at research offices or in the field at a private location convenient and accessible to participants. All aforementioned RDS referral procedures were applied to

participants recruited via online social network strategy, including the same number of referral coupons and incentive structure.

Identifying social network site platforms with a presence of young

transwomen—To explore the social media lives of young transwomen, staff interviewers with extensive knowledge of the community identified trending social network sites with young transwomen as users (shown in Table III). These social network sites span the gamut of static web 1.0 and dynamic web 2.0 functionalities. Many of the static content-based web 1.0 sites function as a personal advertisements/bulletin board whereas web 2.0 sites utilize video, blogging, geospatial location, and mobile phone optimization to fuel dynamic content. Web 2.0 social network sites were primarily centered on dating and community building. Understanding the specific rules of engagement and user etiquette for each site shaped how outreach and recruitment was implemented (e.g. search strategies, content development).

Optimizing search functionality—For social network sites that were transwomenspecific, identifying young transwomen users was determined by each sites' searchability – the function to use search terms within a site's embedded search engine. We used two search techniques: user characteristics and by keyword. Transwomen-specific dating websites often organized its information architecture so that specific user's characteristics listed on users' profiles were easily searchable, such as race, age, location (often by city, state), and physical/bodily attributes like height, measurements, and pre- or post-operative status. We also searched the content of users' profiles by keyword. We developed a comprehensive list of gender identity-related search terms (shown in Table IV). These successful search terms were developed by research staff and confirmed by testing and searching by these keywords in order to locate profiles or users who identify as transwomen.

Creating platform-specific content—Developing a presence on social network sites for recruitment is different for every social network platform. To strengthen the social network presence of the study, we developed platform-specific content for each social network site, focusing on its potential to become viral, or shared among one's online social network. The campaign utilized photos representing racially diverse young transwomen in a variety of social contexts (e.g. urban environments, at school, at work, etc.) combined with the hashtags #ShineOn and #SHINElikeUS, a play on #girlslikeus coined by Janet Mock, a renowned transgender activist and author. Examples of this content can be viewed on our study website (http://www.webcitation.org/6SfEHFj2V) (50). Additionally, we developed content with encouraging messages, branded with study-related hashtags (Figures 3 and 4).

Leveraging the social context of Facebook—Facebook anchored our efforts in the identification and retention of young transwomen online. Facebook served as a direct way for potential and enrolled participants to reach staff asynchronously and in real-time. Due to its popularity among young transwomen, we pointed all social network site traffic to staff profiles and the study Facebook Fan Page. Additionally, we used a Facebook Secret Group to retain enrolled participants over time. Not only did it streamline implementation, recruitment on Facebook was critical to the study's online social network strategy.

Public Facebook profiles allow young transwomen to express their transgender identity in a variety of ways. Unconventional profile content helped to identify young transwomen on Facebook apart from a simple keyword search. We were able to identify potential participants who had a connection with currently enrolled participants and even those proximally connected a few degrees of separation between them, utilizing the "People I May Know" functionality on Facebook Timeline. Individuals with connections represented parts of the network of young transwomen that were embedded but not yet reachable through RDS alone. Another example of unconventional profile content that helped to identify young transwomen were pre- and post-gender transition photos. These photos signaled one's social transition from their assigned sex at birth to another gender. Additionally, Facebook profiles depicted discordant gendered names in the embedded URL for the profile webpage compared to their display name. This was another way to identify a potential participant. At times, Facebook profiles listed membership in popular Facebook groups for young transwomen which also helped to identify potential participants. These were ways the social context of user profiles on Facebook contributed to our online social network strategy.

Social Networking Sampling and Implementation Challenges—Language around gender constantly evolved and the particular use of this language among young transwomen was diverse. This diversity was evident in the varied range of search terms or keywords we found to be successful which make use of already established labels, categories and identifications. They drew from a wide range of terminology spanning the 1950s to contemporary vernacular. Though some of these search terms were anachronistic in use today, they persisted to be used among young transwomen in describing themselves, i.e. some of these terms were considered pejorative slang while others were more politically correct.

Social network sites not specific to transwomen may only include gender identity categories within the male/female binary. This posed an on-going challenge in identifying trans users because having one sole binary gender identification category provided little information as to the user's current gender identification or the gender identity they were assigned at birth. Though recruitment for this study was conducted before Facebook's expansion of users' gender categories, the likelihood of young transwomen continuing to identify as women as opposed to transwomen on social network sites is high due to the prevailing stigma around trans identity.

Our online social network strategy suggests effective ways to reach and involve young transwomen in public health research. Searching by user characteristics, keyword or search terms to reach young transwomen on social network sites were effective. Social network sites like Facebook may create new opportunities to access young transwomen. As social network sites integrate more search functionality and space for trans identities, research methodologies must also adapt. By assessing the social context of profiles, researchers can be more sensitive to diverse gender identity expressions online.

Ethical Considerations—Researchers are beginning to address the rising ethical concerns about collecting data via the Internet and social network sites. Even though social network sites like Facebook allow users to set their own privacy settings, issues like which

profiles and postings are considered public or private are still controversial. Regardless of which postings are public or private, once any data are shared on a social network platform they are often permanent and no longer under the control or ownership of the user (51). In fact, the power that social media platforms have over its users' data is all encompassing. For example, when user preferences have trended toward increased privacy, Facebook has taken steps to curtail these preferences while increasing covert channels of data collection, or "silent listening" (52). Additionally, in June 2014 Facebook published results of a study having exposed users to test the diffusion of emotional contagion, calling into question issues of informed consent, privacy and confidentiality on social media platforms (53). Institutional review boards (IRBs) have been under prepared to address ethical considerations related to research on social network sites (53, 54), especially as findings around best practices are just now being disseminated (55, 56).

Research involving stigmatized behaviors and vulnerable populations have mixed ethical considerations. Despite the sensitivity of researchers using social media to engage users for HIV prevention, a Facebook-based HIV education program in low- and middle-income countries found that researchers' presence on social media platforms were acceptable to participants (57). A systematic review of studies that used Facebook for recruitment found that passive recruitment strategies – advertising, search functionality and creating a Facebook page – were conducted ethically and were effective in recruiting adolescents (58). Research that involved forming one-on-one relationships requiring rapport building posed increased risk for ethical consideration (59).

In the current study, research staff had great access to the online social network lives of potential and enrolled study participants. Though social media technology contributed to our ability to identify young transwomen online, the constant exposure and potential overexposure to participants' lives challenged study staff. Exposure to user generated content that otherwise would have gone unseen to researchers bounded by traditional, brick and mortar methodologies, such as status updates and other public exchanges on social network sites, challenged study staff's conceptions of beneficence and non-maleficence. Research teams should consider implementing regular discussions around the limited role of research staff in observing unanticipated incidents of cyber bullying, depressive episodes, and transphobic hate speech. Protocols and procedures to support the timely response to unanticipated ethical issues are important. Addressing these issues proactively internally can be beneficial in having a sustained, consistent presence of research ethics and the protection of human subjects through all study-related staff interactions.

CONCLUSIONS

In our study, an online social network strategy helped to recruit a large diverse sample of young transwomen. Future continued and sustained research building on the methodology and best practices of integrating online social network strategies in public health epidemiology – perhaps future adaptations of webRDS – is necessary to ensure representative recruitment and sampling of vulnerable and hard-to-reach minority youth. Future studies assessing substantive differences between RDS and strict Internet-based samples of young transwomen are needed. Additionally, qualitative studies examining

implementation of the peer referral process amidst RDS failure may improve decisionmaking and future application of RDS in new populations. As the uptake of social network sites continue to rise especially among vulnerable and hard-to-reach youth, web 2.0 and epidemiology mash-ups – or hybrids – are important and merit scientific exploration and innovation.

ACKNOWLEDGEMENTS

The authors would like to thank all participants in the SHINE study. This study was funded by Award Number R01MH095598 from the National Institutes of Mental Health. The lead author was supported by Award Number T32AA007240, Graduate Research Training on Alcohol Problems, from the National Institute on Alcohol Abuse and Alcoholism. The content is solely the responsibility of the authors and does not necessarily represent the official view of the National Institute on Alcohol Abuse and Alcoholism, the National Institute of Mental Health or the National Institutes of Health.

REFERENCES

- O'Connor A, Jackson L, Goldsmith L, Skirton H. Can I get a retweet please? Health research recruitment and the Twittersphere. Journal of advanced nursing. Mar; 2014 70(3):599–609. PubMed PMID: 23909740. [PubMed: 23909740]
- Yuan P, Bare MG, Johnson MO, Saberi P. Using online social media for recruitment of human immunodeficiency virus-positive participants: a cross-sectional survey. Journal of medical Internet research. 2014; 16(5):e117. PubMed PMID: 24784982. Pubmed Central PMCID: 4026571. [PubMed: 24784982]
- Ramo DE, Rodriguez TM, Chavez K, Sommer MJ, Prochaska JJ. Facebook Recruitment of Young Adult Smokers for a Cessation Trial: Methods, Metrics, and Lessons Learned. Internet interventions: the application of information technology in mental and behavioural health. Apr; 2014 1(2):58–64. PubMed PMID: 25045624. Pubmed Central PMCID: 4100621. [PubMed: 25045624]
- Chu JL, Snider CE. Use of a social networking web site for recruiting Canadian youth for medical research. The Journal of adolescent health: official publication of the Society for Adolescent Medicine. Jun; 2013 52(6):792–4. PubMed PMID: 23352727. [PubMed: 23352727]
- DeHaan S, Kuper LE, Magee JC, Bigelow L, Mustanski BS. The interplay between online and offline explorations of identity, relationships, and sex: a mixed-methods study with LGBT youth. Journal of sex research. 2013; 50(5):421–34. PubMed PMID: 22489658. [PubMed: 22489658]
- Martinez O, Wu E, Shultz AZ, Capote J, Lopez Rios J, Sandfort T, et al. Still a hard-to-reach population? Using social media to recruit Latino gay couples for an HIV intervention adaptation study. Journal of medical Internet research. 2014; 16(4):e113. PubMed PMID: 24763130. Pubmed Central PMCID: 4019772. [PubMed: 24763130]
- Rosser BR, Miner MH, Bockting WO, Ross MW, Konstan J, Gurak L, et al. HIV risk and the internet: results of the Men's INTernet Sex (MINTS) Study. AIDS and behavior. Aug; 2009 13(4): 746–56. PubMed PMID: 18512143. Pubmed Central PMCID: 2718057. [PubMed: 18512143]
- Nemoto T, Operario D, Keatley J, Han L, Soma T. HIV risk behaviors among male-to-female transgender persons of color in San Francisco. American journal of public health. Jul; 2004 94(7): 1193–9. PubMed PMID: 15226142. Pubmed Central PMCID: 1448420. [PubMed: 15226142]
- Baral SD, Poteat T, Stromdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. The Lancet Infectious diseases. Mar; 2013 13(3):214–22. PubMed PMID: 23260128. [PubMed: 23260128]
- Holmberg SD. The estimated prevalence and incidence of HIV in 96 large US metropolitan areas. American journal of public health. May; 1996 86(5):642–54. PubMed PMID: 8629714. Pubmed Central PMCID: 1380471. [PubMed: 8629714]
- Hoffman BR. The interaction of drug use, sex work, and HIV among transgender women. Substance use & misuse. Jun; 2014 49(8):1049–53. PubMed PMID: 24779504. [PubMed: 24779504]

- Garofalo R, Deleon J, Osmer E, Doll M, Harper GW. Overlooked, misunderstood and at-risk: exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. The Journal of adolescent health: official publication of the Society for Adolescent Medicine. Mar; 2006 38(3): 230–6. PubMed PMID: 16488820. [PubMed: 16488820]
- Rapues J, Wilson EC, Packer T, Colfax GN, Raymond HF. Correlates of HIV infection among transfemales, San Francisco, 2010: results from a respondent-driven sampling study. American journal of public health. Aug; 2013 103(8):1485–92. PubMed PMID: 23763398. [PubMed: 23763398]
- Wilson EC, Arayasirikul S, Johnson K. Access to HIV Care and Support Services for African American Transwomen Living with HIV. International Journal of Transgenderism. Oct 01; 2013 14(4):182–95. 2013. [PubMed: 24817835]
- Poteat T, Reisner SL, Radix A. HIV epidemics among transgender women. Current opinion in HIV and AIDS. Mar; 2014 9(2):168–73. PubMed PMID: 24322537. [PubMed: 24322537]
- Heckathorn DD. Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. Social Problems. 1997; 44(2):174–99.
- Johnston LG, Sabin K, Mai TH, Pham TH. Assessment of respondent driven sampling for recruiting female sex workers in two Vietnamese cities: reaching the unseen sex worker. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i16–28. PubMed PMID: 17031567. Pubmed Central PMCID: 1705478. [PubMed: 17031567]
- Stormer A, Tun W, Guli L, Harxhi A, Bodanovskaia Z, Yakovleva A, et al. An analysis of respondent driven sampling with Injection Drug Users (IDU) in Albania and the Russian Federation. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i73–82. PubMed PMID: 17075727. Pubmed Central PMCID: 1705474. [PubMed: 17075727]
- Platt L, Wall M, Rhodes T, Judd A, Hickman M, Johnston LG, et al. Methods to recruit hard-toreach groups: comparing two chain referral sampling methods of recruiting injecting drug users across nine studies in Russia and Estonia. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i39–53. PubMed PMID: 17096189. Pubmed Central PMCID: 1705540. [PubMed: 17096189]
- McKnight C, Des Jarlais D, Bramson H, Tower L, Abdul-Quader AS, Nemeth C, et al. Respondent-driven sampling in a study of drug users in New York City: notes from the field. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i54–9. PubMed PMID: 16977493. Pubmed Central PMCID: 1705505. [PubMed: 16977493]
- Scheim AI, Bauer GR. Sex and Gender Diversity Among Transgender Persons in Ontario, Canada: Results From a Respondent-Driven Sampling Survey. Journal of sex research. Apr.2014 21:1–14. PubMed PMID: 24750105. [PubMed: 24750105]
- Silva-Santisteban A, Raymond HF, Salazar X, Villayzan J, Leon S, McFarland W, et al. Understanding the HIV/AIDS epidemic in transgender women of Lima, Peru: results from a seroepidemiologic study using respondent driven sampling. AIDS and behavior. May; 2012 16(4):872– 81. PubMed PMID: 21983694. [PubMed: 21983694]
- 23. Santos GM, Rapues J, Wilson EC, Macias O, Packer T, Colfax G, et al. Alcohol and substance use among transgender women in San Francisco: prevalence and association with human immunodeficiency virus infection. Drug and alcohol review. May; 2014 33(3):287–95. PubMed PMID: 24628655. [PubMed: 24628655]
- 24. Yeka W, Maibani-Michie G, Prybylski D, Colby D. Application of respondent driven sampling to collect baseline data on FSWs and MSM for HIV risk reduction interventions in two urban centres in Papua New Guinea. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i60–72. PubMed PMID: 17066328. Pubmed Central PMCID: 1705546. [PubMed: 17066328]
- 25. Johnston LG, Khanam R, Reza M, Khan SI, Banu S, Alam MS, et al. The effectiveness of respondent driven sampling for recruiting males who have sex with males in Dhaka, Bangladesh. AIDS and behavior. Mar; 2008 12(2):294–304. PubMed PMID: 17712620. [PubMed: 17712620]
- 26. Wejnert C. Web-based network sampling efficiency of of respondent-driven sampling for online research. Sociological Methods & Research. 2008; 37(1):105–34.

- 27. Simic M, Johnston LG, Platt L, Baros S, Andjelkovic V, Novotny T, et al. Exploring barriers to 'respondent driven sampling' in sex worker and drug-injecting sex worker populations in Eastern Europe. Journal of urban health: bulletin of the New York Academy of Medicine. Nov; 2006 83(6 Suppl):i6–15. PubMed PMID: 17109206. Pubmed Central PMCID: 1705510. [PubMed: 17109206]
- Ellson J, Gansner E, Koutsofios E, North S, Woodhull G. Graphviz Open Source Graph Drawing Tools. Graph Drawing. 2001:483–4.
- 29. Inc SI. SAS/STAT Software, Version 9.3. 2011.
- Baral SD, Poteat T, Guadamuz TE, Beyrer C. Sampling bias in transgender studies--authors' reply. The Lancet infectious diseases. Oct; 2013 13(10):832–3. PubMed PMID: 24070556. [PubMed: 24070556]
- Bauer GR, Scheim AI. Sampling bias in transgender studies. The Lancet infectious diseases. Oct. 2013 13(10):832. PubMed PMID: 24070555. [PubMed: 24070555]
- Grossman AH, D'Augelli AR. Transgender youth: invisible and vulnerable. Journal of homosexuality. 2006; 51(1):111–28. PubMed PMID: 16893828. [PubMed: 16893828]
- 33. Bauermeister JA, Zimmerman MA, Johns MM, Glowacki P, Stoddard S, Volz E. Innovative recruitment using online networks: lessons learned from an online study of alcohol and other drug use utilizing a web-based, respondent-driven sampling (webRDS) strategy. Journal of studies on alcohol and drugs. Sep; 2012 73(5):834–8. PubMed PMID: 22846248. Pubmed Central PMCID: 3410951. [PubMed: 22846248]
- 34. Truong HM, Grasso M, Chen YH, Kellogg TA, Robertson T, Curotto A, et al. Balancing theory and practice in respondent-driven sampling: a case study of innovations developed to overcome recruitment challenges. PloS one. 2013; 8(8):e70344. PubMed PMID: 23990901. Pubmed Central PMCID: 3749182. [PubMed: 23990901]
- Sadasivam RS, Volz EM, Kinney RL, Rao SR, Houston TK. Share2Quit: Web-Based Peer-Driven Referrals for Smoking Cessation. JMIR research protocols. 2013; 2(2):e37. PubMed PMID: 24067329. Pubmed Central PMCID: 3786127. [PubMed: 24067329]
- Bengtsson L, Lu X, Nguyen QC, Camitz M, Hoang NL, Nguyen TA, et al. Implementation of webbased respondent-driven sampling among men who have sex with men in Vietnam. PloS one. 2012; 7(11):e49417. PubMed PMID: 23152902. Pubmed Central PMCID: 3495883. [PubMed: 23152902]
- 37. Stein ML, van Steenbergen JE, Chanyasanha C, Tipayamongkholgul M, Buskens V, van der Heijden PG, et al. Online respondent-driven sampling for studying contact patterns relevant for the spread of close-contact pathogens: a pilot study in Thailand. PloS one. 2014; 9(1):e85256. PubMed PMID: 24416371. Pubmed Central PMCID: 3885693. [PubMed: 24416371]
- DiClemente RJ, Ruiz MS, Sales JM. Barriers to adolescents' participation in HIV biomedical prevention research. Journal of acquired immune deficiency syndromes. Jul; 2010 54(Suppl 1):S12–7. PubMed PMID: 20571418. Pubmed Central PMCID: 2925395. [PubMed: 20571418]
- Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, et al. Reaching the hard-toreach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. BMC medical research methodology. 2014; 14:42. PubMed PMID: 24669751. Pubmed Central PMCID: 3974746. [PubMed: 24669751]
- 40. Miller MK, Wickliffe J, Jahnke S, Linebarger JS, Dowd D. Accessing General and Sexual Healthcare: Experiences of Urban Youth. Vulnerable children and youth studies. Jul 1; 2014 9(3): 279–90. PubMed PMID: 25101138. Pubmed Central PMCID: 4119761. [PubMed: 25101138]
- Valaitis R. "They don't trust us; we're just kids:" views about community from predominantly female inner city youth. Health care for women international. Apr-May;2002 23(3):248–66. PubMed PMID: 12003503. [PubMed: 12003503]
- 42. Brawner BM, Volpe EM, Stewart JM, Gomes MM. Attitudes and beliefs toward biobehavioural research participation: voices and concerns of urban adolescent females receiving outpatient mental health treatment. Annals of human biology. Nov-Dec;2013 40(6):485–95. PubMed PMID: 23822716. [PubMed: 23822716]
- 43. Heckathorn DD. Respondent-Driven Sampling II: Deriving Valid Population Estimates from Chain-Referral Samples of Hidden Populations. Social Problems. 2002; 49(1):11–34.

- 44. Zembe YZ, Townsend L, Thorson A, Ekstrom AM. Predictors of inconsistent condom use among a hard to reach population of young women with multiple sexual partners in peri-urban South Africa. PloS one. 2012; 7(12):e51998. PubMed PMID: 23284847. Pubmed Central PMCID: 3527429. [PubMed: 23284847]
- 45. Kuhns LM, Kwon S, Ryan DT, Garofalo R, Phillips G 2nd, Mustanski BS. Evaluation of Respondent-Driven Sampling in a Study of Urban Young Men Who Have Sex with Men. Journal of urban health: bulletin of the New York Academy of Medicine. Aug 16.2014 PubMed PMID: 25128301.
- 46. Phillips G 2nd, Kuhns LM, Garofalo R, Mustanski B. Do recruitment patterns of young men who have sex with men (YMSM) recruited through respondent-driven sampling (RDS) violate assumptions? Journal of epidemiology and community health. Aug 1.2014 PubMed PMID: 25086159.
- McCreesh N, Frost SD, Seeley J, Katongole J, Tarsh MN, Ndunguse R, et al. Evaluation of respondent-driven sampling. Epidemiology. Jan; 2012 23(1):138–47. PubMed PMID: 22157309. Pubmed Central PMCID: 3277908. [PubMed: 22157309]
- Santos GM, Wilson EC, Rapues J, Macias O, Packer T, Raymond HF. HIV treatment cascade among transgender women in a San Francisco respondent driven sampling study. Sexually transmitted infections. Apr 8.2014 PubMed PMID: 24714446.
- Wilson E, Rapues J, Jin H, Raymond HF. The use and correlates of illicit silicone or "fillers" in a population-based sample of transwomen, San Francisco, 2013. The journal of sexual medicine. Jul; 2014 11(7):1717–24. PubMed PMID: 24810672. Pubmed Central PMCID: 4304636. [PubMed: 24810672]
- 50. The SHINE Study Web Site [Internet]. Sep 17. 2014 [cited 2014-09-17]. Available from: http://www.theshinestudy.org
- 51. Hull G, Lipford HR, Latulipe C. Contextual gaps: Privacy issues on Facebook. Ethics and information technology. 2011; 13(4):289–302.
- 52. Stutzman F, Gross R, Acquisti A. Silent listeners: The evolution of privacy and disclosure on facebook. Journal of privacy and confidentiality. 2013; 4(2):2.
- 53. Kleinsman J, Buckley S. Facebook study: a little bit unethical but worth it? J Bioeth Inq. Jun; 2015 12(2):179–82. PubMed PMID: 25740760. [PubMed: 25740760]
- Moreno MA, Goniu N, Moreno PS, Diekema D. Ethics of social media research: common concerns and practical considerations. Cyberpsychology, behavior and social networking. Sep; 2013 16(9):708–13. PubMed PMID: 23679571. Pubmed Central PMCID: 3942703.
- 55. Curtis BL. Social Networking and Online Recruiting for HIV Research: Ethical Challenges. Journal of Empirical Research on Human Research Ethics: An International Journal. 2014; 9(1): 58–70.
- 56. Bull SS, Breslin LT, Wright EE, Black SR, Levine D, Santelli JS. Case study: An ethics case study of HIV prevention research on Facebook: the Just/Us study. J Pediatr Psychol. Nov-Dec;2011 36(10):1082–92. PubMed PMID: 21292724. Pubmed Central PMCID: 3199441. [PubMed: 21292724]
- Chiu CJ, Menacho L, Fisher C, Young SD. Ethics Issues in Social Media-Based HIV Prevention in Low- and Middle-Income Countries. Camb Q Healthc Ethics. Jul; 2015 24(3):303–10. PubMed PMID: 26059956. [PubMed: 26059956]
- Amon KL, Campbell AJ, Hawke C, Steinbeck K. Facebook as a recruitment tool for adolescent health research: a systematic review. Acad Pediatr. Sep-Oct;2014 14(5):439–47. e4. PubMed PMID: 25169155. [PubMed: 25169155]
- Valdez RS, Guterbock TM, Thompson MJ, Reilly JD, Menefee HK, Bennici MS, et al. Beyond traditional advertisements: leveraging Facebook's social structures for research recruitment. Journal of medical Internet research. 2014; 16(10):e243. PubMed PMID: 25348050. Pubmed Central PMCID: 4259909. [PubMed: 25348050]

Arayasirikul et al.

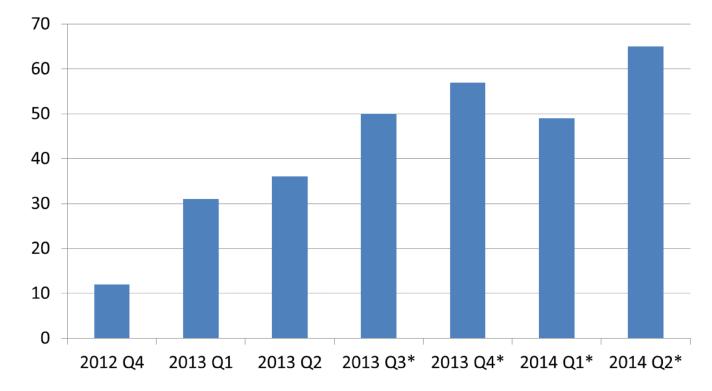
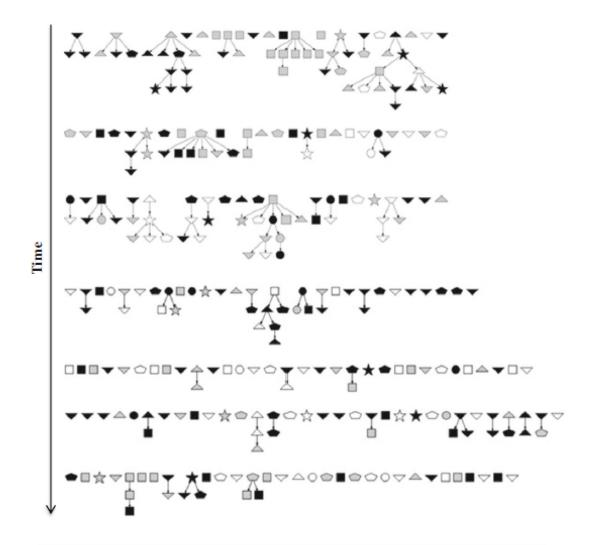


Figure 1.

Participant enrollment over time by quarter, 2012-2014

*denotes recruitment period during which online social network recruitment was

implemented



Legend	
Race = shape	Shading = gender identity
Asian = circle	Female = black
African American = triangle	Transgender female/transwoman = gray
Latina = square	Other = white
Mixed = pentagon	
White = inverted triangle	
Other = star	

Figure 2.

Peer referral chains among young transwomen in San Francisco, 2012-2014



Figure 3. Example of platform-specific content developed for recruitment



Figure 4. Example of platform-specific content developed for recruitment

Table I

Mean Network Size and Homophily by Race/Ethnicity and Gender Identity among Young Transwomen in the San Francisco Bay Area, 2012-2014

Network Size			
Total # of young transwomen you know in the SF Bay Area?			
Total # of young transwomen you would I	be willing to give a referral coupor	n to? 5.46	
Homophily	Coefficient		
Race/Ethnicity			
Black	0.47		
Asian	0.41		
Hispanic	0.31		
White	0.18		
Mixed	-0.01		
Gender Identity			
Transgender female or transwoman	0.32		
Non-binary gender	0.23		
Female	0.17		

Table II

Demographic Characteristics of Young Transwomen in the San Francisco Bay Area Stratified by Recruitment $Period^a$

	Total (N=300)	Time 1 (n=79)	Time 2 (n=221)	X^2	Р
ge (n=300)					
16-18	42 (14.0)	6 (5.9)	36 (18.2)		0.0269
19-20	57 (19.0)	21 (20.6)	36 (18.2)	0.10	
21-23	159 (53.0)	57 (55.9)	102 (51.5)	9.19	
24	42 (14.0)	18 (17.7)	24 (12.1)		
ender (n=300)		•			
Female	133 (44.3)	50 (49.0)	83 (41.9)		
Trans female	100 (33.3)	38 (37.3)	62 (31.3)	10.4247	0.0339
Non-binary gender	67 (22.3)	14 (13.8)	53 (26.8)		
ace (n=300)					
Hispanic	93 (31.0)	32 (31.4)	61 (30.8)		0.3721
White	107 (35.7)	35 (34.3)	72 (36.4)		
Black	36 (12.0)	16 (15.7)	20 (10.1)	4.2588	
Asian	18 (6.0)	3 (2.9)	15 (7.6)		
Other/mixed	46 (15.3)	16 (15.7)	30 (15.2)		
ducation (n=300)					
Less than high school	61 (20.3)	25 (24.5)	36 (18.2)	7.4771	0.0581
High school	101 (33.7)	41 (40.2)	60 (30.3)		
Some college	105 (35.0)	26 (25.5)	79 (39.9)		
College graduate/Graduate school	33 (11.0)	10 (9.8)	23 (11.6)		
Ionthly Income (n=297)					
0-500	156 (52.5)	58 (57.4)	98 (50.0)		0.4292
501-1000	63 (21.2)	17 (16.8)	46 (23.5)	3.8322	
1001-1500	28 (9.4)	7 (6.9)	21 (10.7)		
1501-2000	21 (7.1)	9 (8.9)	12 (6.1)		
2000+	29 (9.8)	10 (9.9)	19 (9.7)		
istory of Housing Instability (n=300)					
Ever had unstable housing	170 (56.7)	70 (68.6)	100 (50.5)	9.0038	0.002
Ever run away from home	156 (52.0)	66 (64.7)	90 (45.5)	12.02764	0.005
listory of Sex Work (n=300)					

 a Time 1 – RDS-only, Time 2 – Online Social Network Sampling + RDS

Trending Social Network Sites

Social Network Site Type		Purpose	
Transgenderdate.com	Web 1.0 Social Network Site	Dating – Transwomen-specific	
Tsdating.com	Web 1.0 Social Network Site	Dating – Transwomen-specific	
Myredbook.com	Web 1.0 Social Network Site	Dating – Transwomen-specific	
Craigslist.com	Web 1.0 Social Network Site	Dating – Transwomen-specific	
Grindr	Web 2.0 Geospatial Mobile App	Dating - Not transwomen-specific	
Blendr	Web 2.0 Geospatial Mobile App	Dating - Not transwomen-specific	
Scruff	Web 2.0 Geospatial Mobile App	Dating - Not transwomen-specific	
OkCupid	Web 2.0 Social Network Site & Geospatial Mobile App	Dating – Not transwomen-specific	
Tumblr	Web 2.0 Microblogging Social Network Site	Interest-driven Community Building	
Youtube	Web 2.0 Video Sharing Site	Interest-driven Community Building	
Facebook	Web 2.0 Social Network Site	Friendship-driven Community Building	

Table IV

Search Terms

Search Terms	Socio-cultural Context
Trans*female	Contemporary
Transgender woman	
Transwoman	
Trans	
Transexual/Transsexual	Anachronistic
Transvestite	
Male-to-Female/MTF/M2F	
Tgirl/TG	
Tranny	Anachronistic, degrading
Shemale	
Lady Boy	
Androgynous	Gender non-conforming, non-binary
Genderfluid/Genderqueer	