**Formative research to optimize Respondent Driven Sampling surveys among hard to reach populations in HIV behavioral and biological surveillance: Lessons learned from four countries**

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<th>Journal:</th>
<th>AIDS Care - Psychology, Health &amp; Medicine - Vulnerable Children and Youth Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manuscript ID:</td>
<td>AC-2009-05-0252.R1</td>
</tr>
<tr>
<td>Journal Selection:</td>
<td>AIDS Care</td>
</tr>
<tr>
<td>Keywords:</td>
<td>HIV/AIDS, vulnerable populations, HIV risk behaviors, respondent driven sampling, qualitative methods</td>
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Formative research to optimize Respondent Driven Sampling surveys among hard to reach populations in HIV behavioral and biological surveillance:

Lessons learned from four case studies

Acknowledgements: We wish to thank the following persons and groups for their collaboration in conducting formative research in their respective countries: Dr Natasa Loncarevic, HIV/AIDS Coordinator for Republica Srpska, Bosnia and Herzegovina and UNICEF office in Sarajevo; Chomnad Manopaiboon and Dr. Kimberley Fox, Thailand MOPH – U.S. CDC; Dr. Gaëlle Bombereau and Suzanne Ogunnaike-Cooke.

Disclaimer: The findings and conclusions in this paper are those of the authors and do not necessarily represent those of the Centers for Disease Control and Prevention.

Word count: Abstract, 171; manuscript 3290, excluding references
INTRODUCTION

Respondent driven sampling (RDS) is currently a popular sampling method to assess HIV and other sexually transmitted infections (STIs) prevalence and risk behaviors from hard-to-reach populations. Developed as a relatively easy-to-implement and effective sampling method to gather representative data from socially networked populations (Heckathorn, 2002; 1997), RDS has been adopted by public health specialists to assess the HIV epidemic among injecting drug users (IDUs), female sex workers (FSWs) and males who have sex with males (MSM) (Johnston, Malekinejad, Kendall, Iuppa, & Rutherford, 2009; Malekinejad, et al., 2008). However, RDS is a fairly new sampling method and attempts to implement surveys using RDS have failed in some settings.

RDS begins with a small number of participants (seeds) who are non-randomly selected from the target population. Enrollees are provided a fixed number of coupons to use in recruiting their peers, i.e. other target population members. Upon presenting a valid coupon at an RDS survey site, a recruit can enroll and participate in the survey, and in turn, receive coupons to use in recruiting peers. This process should result in lengthy recruitment 'waves' which make up recruitment chains of diverse members of the sampled population.

To encourage recruitment, participants are usually provided an incentive to complete the survey (primary incentive) and to recruit their peers (secondary incentive). Data are analyzed using the RDS analysis tool (RDSAT), or some other analysis program that adjusts for biases related to the sampling and when properly implemented and analyzed RDS data can provide estimates representative of the target population (Heckathorn 2002; 1997; Salganik & Heckathorn 2004).

One proposed advantage of RDS is that no formative research is required (Magnani, Sabin, Saidel, & Heckathorn, 2005; Semaan, Lauby, & Liebman, 2002). However, some researchers who conduct RDS find that formative research is an essential step for ensuring successful survey outcomes (Simic, et al., 2006). Although there is currently an expanding body
of literature on RDS methods and outcomes (Malekinejad et al, 2008; Abu-Quedar, Heckathorn, Sabin & Saidel, 2006), we are not aware of any literature that addresses the role of formative research in optimizing the use of RDS to survey hard-to-reach populations.

For the purposes of this paper, formative research is defined as pre-planned, systematic and formal. It uses a range of rapid assessment techniques to explore key issues in implementing subsequent research or program activities. Investigation is exploratory, multi-method and opportunistic and can include various qualitative, quantitative or archival methods. Techniques include conventional and in-depth interviews, useful for gathering information from individuals in the target population; focus group discussions (FGDs), useful for gathering socially acceptable or group mediated information and observing dynamics and dialogue; key informant and expert interviews, useful for gathering information from gatekeepers and professional personnel in organizations and government agencies who work directly with the target population; and structured and unstructured observation, useful for facility-based and community data collection (Tong, Sainsbury, & Craig, 2007; Mays & Pope, 2005; Silverman, 2004; Bernard, 2002).

This paper describes formative research used to plan four RDS HIV behavioral and biological surveys among three different populations. Formative research designs were not uniform across the surveys. We propose that formative research may help researchers to determine whether RDS is an appropriate sampling method for a particular population and socio-cultural context, and to decide on implementation details that lead to successful surveys. This may prevent wasting vital HIV surveillance funds.

METHODS

Formative research protocols were implemented in preparation for RDS surveys in the following locations and risk groups: Banja Luka, Bosnia and Herzegovina (IDUs), Bangkok, Thailand (FSWs), Podgorica, Montenegro (FSWs), and St. Vincent’s & Grenadine Islands (SVG), Eastern Caribbean (MSM).
Each of the surveys included essential RDS elements, such as initiating recruitment with a non-random selection of seeds, a quota of recruitment coupons per participant, incentives for participation and peer recruitment, collection of social network size data and tracking recruitment chains (Table 1). Interviewing methods, incentives and specimen collection varied by location. Surveys were approved through respective ethical review committees. RDS had not been previously used among the sampled population in any of these locations.

An overview of the formative research methods used in each country is presented in table 2. All formative research used semi-structured questionnaires, including questions described in table 3. Key findings were reviewed and discussed by project teams to share impressions and common or convergent themes across interviews, organized by theme and included in a final summary of findings.

Table 3 presents a template of suggested formative research questions useful for planning RDS surveys. Formative research may address social network properties, acceptability of RDS to the target population, seed selection and survey logistics.

**Social Networks**

The exploration of social networks is essential for determining whether the target population can maintain RDS recruitment. There are several aspects of social networks to consider for optimizing RDS including *degree* (number of ties within a social network), whether networks form isolated *cliques* or sub-networks, and if so whether there are *bridges* which can be targeted to ensure connections between these cliques. Bridges ensure that important sub-groups within a social network are sampled (e.g., transsexuals in a social network of MSM or FSWs working in distinct areas in a city). In the absence of bridges between cliques, the final survey population could form two or more independent samples (social network structures) that need to be analyzed as such; or important subgroups may be missed altogether.
Finally, it is important to understand the strength of ties (weak or strong) within social networks. Having both weak and strong ties can assist in RDS recruitment, whereas just having strong ties may indicate less social diffusion throughout the network. Ties can be assessed through degree (Granovetter, 1973) and should be linked through multiple types of relationships (e.g., friendships, acquaintances, co-workers, room-mates) and activities. Ideally, degrees should be large enough (≥ 3) to sustain recruitment and develop the long recruitment chains needed for RDS analysis.

**Acceptability of RDS**

The peer recruitment sampling used in RDS relies on its acceptability to the target population. Acceptability may be influenced by stigma or legal sanctions associated with target population behaviors, confidence that survey staff can maintain confidentiality, level of trust in the organizations conducting the survey or in institutions generally, incentive levels, and the convenience of the survey site’s location and operating hours. Some of these factors are outside the control of researchers; others can be addressed by tailoring survey logistics appropriately as discussed below.

**Seed Selection**

Seeds should comprise target population members with large degree (many ties) made up of multiple types of relationships, activities and subgroups. “Good” seeds will improve recruitment effectiveness by supporting the survey goals and persuading others to participate. Seeds with diverse characteristics and social relationships within a social network will speed up the recruitment of a social mix of participants representing the target population (Heckathorn, 1997; 2002).

**Survey Logistics**

Formative assessment can assist in determining acceptable incentives for enrolling in a survey and recruiting peers, finding appropriate survey locations, setting the hours and days of
operation and the type and sex of the survey staff and providing important information about coupon design (colors, pictures, map, language(s) and literacy considerations).

FORMATIVE RESEARCH FINDINGS

*Banja Luka, Bosnia and Herzegovina*

Interviewed IDUs reported degree sizes ranging from 4-20 and formed strong ties as close knit injection groups (cliques) of 4-5, but also formed weaker ties through friendships, drug purchases and sales and attending treatment agencies. IDUs expressed interest in participating in an RDS survey, but were concerned about potential threats from the police. Interviewees suggested that seeds with diverse characteristics would be easily found. Incentive type and value were suggested through interviews with staff familiar with past IDU surveys and confirmed through IDU FGDs. Interviews and FGDs indicated few appropriate survey sites were available and that out-of-clinic settings were preferred.

*Bangkok, Thailand*

Interviewed FSWs reported degree sizes ranging from 1-20 and indicated that FSWs form strong and weak ties through their relationships as friends, acquaintances and co-workers. FSWs comprised cliques in four major sex work areas and indicated that few FSWs formed bridges across these cliques. Lower-paid FSWs, most of whom had previous interaction with outreach staff, were more interested in participating in the survey than were higher-paid FSWs. Interviews indicated that incentives would be difficult to set since having one incentive level might be too low for higher-paid FSWs and too high for lower-paid FSWs. Interviewees suggested few available interview sites, that public health clinics were not acceptable, and that given the traffic in Bangkok multiple survey sites close to working areas would be needed. Interviewed FSWs preferred afternoon and evening interview sites, staffed by people already working with FSWs, and a coupon designed with a map of survey locations.

*Podgorica, Montenegro*
Finding FSWs for FGDs was difficult; FSWs were not observed in visible areas. Interviews with FSWs indicated degree sizes of up to 20; however the network structure comprised isolated cliques formed around brothels that restricted their movement. FSWs did not normally form friendships with other FSWs due to language barriers (trafficking of FSWs from other countries) and restricted movement. Anti-trafficking organization staff reported being threatened by persons in control of the brothels. Interviews with FSWs indicated that they wanted an incentive equivalent to the amount paid them by clients. Interviews with FSWs and NGOs indicated few appropriate survey sites available, and that out-of-clinic settings and late afternoon hours were preferred. No preferences were suggested for staffing. Interviews and observations suggested seeds would be extremely difficult to locate and that FSWs would be reluctant to enroll in the survey.

St Vincent & Grenadines, Eastern Caribbean

Interviews with MSM indicated small degree sizes ranging from 2-5 and weak social network ties among MSM. Interviewed MSM were reluctant to discuss their behaviors and showed only moderate interest in the survey (Ogunnaike-Cooke & Bombereau, 2007). Observation and interviews with NGOs indicated extremely high levels of community stigma about AIDS and MSM (e.g., “MSM are the cause of AIDS”). Formative research suggested the non-monetary incentive proposed for the survey would not be sufficient to outweigh the risks of enrolling in the survey. MSM and NGO interviews indicated that few options were available for a survey location, out-of-clinic settings were preferred, and that MSM interviewers were preferred.

RDS SURVEY OUTCOMES

Formative research findings indicated that RDS recruitment would be successful among IDUs in Banja Luka and FSWs in Bangkok. An average of six IDUs enrolled daily in Banja Luka producing 12 recruitment waves and a final sample of 263 enrolled. Seven seeds were identified during formative research and varied by age, duration of drug use and gender. Two seeds were added later in the survey to speed up recruitment. In response to IDU fears of police
harassment during the survey, RDS staff convinced police to cease crime prevention activities near the survey site during the survey. A private house next to an NGO known by IDUs served as the survey site and blinds were added to ensure participants’ anonymity.

In Bangkok an average of 25 FSWs enrolled at three sites daily, producing 11 recruitment waves and a final sample of 703. Seeds, identified through local NGO staff, worked in different areas, and differed by ability to recruit FSWs in other areas, level of earnings, age and years as a FSW. Seeds were selected to ensure that the final sample would comprise one social network rather than four distinct social networks representing the geographic pattern of FSWs in Bangkok. Only ten of the fifteen seeds became effective recruiters.

Formative research indicated that higher-paid FSWs would be less interested in participating in the survey than lower-paid FSWs, due to the level of incentive and to their lack of exposure to outreach work or previous surveys. In response to this finding, an NGO was contracted to conduct preparatory work (outreach/condom distribution) among higher-paid FSWs with the goal of increasing their exposure to prevention programs and willingness to interact with interviewers. Lower-paid FSWs found the survey incentive attractive and in two locations perceptions of a high incentive led to coupon selling and FSWs trying to enroll more than once. Overall, recruitment of lower-paid FSWs was faster than for higher-paid FSWs. As requested by FSWs, interviews were conducted during afternoons and evenings, staff comprised persons already working with FSWs, and non-clinic survey sites were located in different areas of the city; one site in a hotel, one in a storefront behind a food vendor, and one in a hair salon.

Formative research findings indicated that RDS would not be successful among FSWs in Podgorica and it was unclear whether RDS would be successful among MSM in SVG. Finding TPMs in both settings was difficult. In Podgorica, RDS was initiated in September 2005 and terminated four weeks later. Originally four seeds, found through key informants, agreed to enroll but only one seed actually enrolled in the survey and received three coupons but recruited
no further participants. As requested by interviewed FSWs, the survey location was in a non-clinic setting and sites were open during late afternoon hours. Further efforts to locate additional FSWs to enroll in the survey were unsuccessful.

In SVG, initially four MSM found through a local NGO expressed interest in being seeds for the RDS survey. Only one seed arrived at the survey site at his appointment time. Staff had to make several calls to encourage the other three seeds to enroll; these seeds enrolled a week later. By week two only two seeds recruited two MSM. In week 11 another MSM was recruited from one of the original seeds but none of the recruitment chains produced more than one wave. The survey site was located in an NGO office building located just outside of the center of the city. Non-MSM male staff were contracted from local NGOs working with HIV/AIDS issues, despite formative research indicating that staff should comprise MSM.

DISCUSSION

Each of the four studies described here used multi-method qualitative approaches to plan implementation of RDS HIV surveys among hard-to-reach populations. The RDS surveys of IDUs in Banja Luka and FSWs in Bangkok were successful, while the surveys of FSWs in Podgorica and MSM in SVG were terminated in advance of reaching their sample sizes.

Surveys conducted in Banja Luka and Bangkok gathered information through formative research that clearly indicated the acceptability of RDS and that degree size and other social network properties were sufficient for RDS recruitment. Formative research provided important leads for identifying seeds, incentives, survey staff and sites and coupon design. Furthermore, finding population members to participate in formative research was easy. This presaged easy recruitment for the surveys.

Some findings from the formative research in Podgorica and SVG indicated that RDS recruitment would not succeed. First, FSWs and MSM in these cities were reluctant to participate in formative research and those that did indicated inadequate network properties (cliques among FSWs, small degree sizes among MSM) to sustain peer to peer recruitment.
Furthermore, MSM in SVG were subject to an obvious high level of community stigma and widespread misperceptions about the relationship of MSM to HIV. In Podgorica FSWs were highly restricted in their movement and not easily accessed by researchers. It appears in both of these examples that the quality of logistics, such as a private, comfortable and accessible survey locations, reasonable incentives and appropriate staffing (although no MSM could be found to serve as staff in SVG) could not outweigh the perceived consequences of enrolling in the survey. It is unknown whether more comprehensive formative work with MSM in SVG (only two were interviewed) would have clarified the potential to overcome MSM concerns or respond to their needs. Further exploration of the well-known and documented issues of homophobia in the English-speaking Caribbean would have been appropriate. In both cases, information gathered warranted not proceeding with RDS in these settings.

Possible barriers to recruitment were found and addressed during formative research. For instance, in Bangkok formative research showed that FSWs who had not received outreach services were less interested in participating in the survey than those who had. Other surveys of FSWs indicate that exposure to outreach services may influence trust and interest to participate in research projects (Simic et al., 2006). Before commencing the RDS survey Bangkok researchers contracted a local NGO to conduct preparatory outreach and condom distribution in the area where FSWs seemed reluctant to participate. The RDS survey was then successful in recruiting from this area, though this cannot necessarily be attributed to the outreach work.

Formative research can be essential for locating adequate seeds. All four surveys found some or all seeds during the formative research process. Often individuals willing to participate in formative research activities may have previous research experience or have some interest in the survey goals, thereby becoming effective seeds.

A limitation to this review is that there were no standard indicators to assess the quality of the formative research conducted. There are a broad range of other issues relevant to RDS that were not explored in the formative research used here, for example, whether biological...
testing influences willingness to participate. This and a range of other potential issues are outlined in a RDS training manual developed by the first author (2007). In two of the surveys, it is likely that an insufficient number of key informants were interviewed. Furthermore, operationalization of the questions outlined in Table 3 was not standardized. A limitation of this analysis is that we did not compare RDS surveys using vs. not using systematic formative research. We therefore cannot demonstrate with our evidence here that formative research changes survey outcomes.

Formative research by its nature is not definitive and is not designed to test hypotheses but rather to contribute to the survey planning process. Research teams and funders need to be prepared to act on the findings, including consideration of canceling RDS survey plans if it is apparent that a given setting is not appropriate for the method. There is always an element of risk in securing ongoing recruitment using RDS in new regions among poorly studied populations, especially among populations that are highly stigmatized, poorly networked, not exposed to outreach services, or faced with serious legal sanctions for their behaviors (Simic et al., 2006). Once RDS data collection begins, altering survey logistics to bolster recruitment may be difficult, costly and disruptive. Because RDS recruitment success demands such a high level of support and commitment from the target population, most surveys can benefit from formative preparation to ensure acceptability and appropriateness in a specific setting, comparable to that done for health intervention development (Gittelsohn, et al., 2006; Higgins, et al., 1996).

Formative research, if conducted appropriately, can contribute to RDS planning by describing the target populations’ social network properties, identifying useful seeds, measuring surveillance acceptability and informing RDS survey logistics. Formative research is often the first contact by researchers with the community and news of the research will spread through the community. It also demonstrates that the survey staff are willing to listen to the community, and make changes in the survey. Most importantly, formative research can help inform whether
RDS is an appropriate method for a particular population and socio-cultural context. This is most obviously seen in Podgorica among FSWs and SVG among MSM.

The formative research surveys outlined here led in some cases to survey planners substantially altering plans or initiating additional preparatory work to ensure successful implementation of RDS surveys; in others, surveys proceeded despite evidence that the RDS was not appropriate for the setting. Unfortunately many survey planners do not budget for formative research before survey implementation. It is hoped that the illustrative examples outlined in this paper will influence researchers and administrators to focus more resources on formative work prior to RDS and that formative research findings will assist in the smooth implementation and successful outcomes of future RDS surveys.

REFERENCES


http://mc.manuscriptcentral.com/ac-phm-vcy


Table 1. Overview of RDS Surveys in each country

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<thead>
<tr>
<th>Target Pop.</th>
<th>Eligibility</th>
<th>Target sample size</th>
<th>Incentive</th>
<th>Biological specimen</th>
<th>Interview format</th>
<th>Date</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Banja Luka, Bosnia &amp; Herzegovina</td>
<td>Injecting drug users; Injected drugs in past month; aged 18 years + (if under 18 year, possibility of providing only behavioral data); living within Banja Luka municipality.</td>
<td>200</td>
<td>Primary incentive at USD 13.40; secondary incentive at USD 6.85.</td>
<td>5 mL of venous blood to test for HIV, HVB, HVC</td>
<td>40-minute, face-to-face</td>
<td>Fall 2007</td>
<td>Test results offered on site; pre and post test counseling</td>
</tr>
<tr>
<td>Bangkok, Thailand</td>
<td>Female sex workers; Women selling sex for money or goods in past month; aged 15 years +; living or working in Bangkok.</td>
<td>700</td>
<td>Primary incentive at USD 12.50; secondary incentive at USD 1.60.</td>
<td>oral fluid specimen to test for HIV; urine to test for <em>N. gonorrhoeae</em>, <em>Chlamydia trachomatis</em></td>
<td>30-minute, ACASI</td>
<td>Fall 2007</td>
<td>Test results offered on site; clinic referrals for follow up care</td>
</tr>
<tr>
<td>Podgorica, Montenegro</td>
<td>Female sex workers; Females, selling sex for money or goods in past six months; aged 18 years +; living or working in Podgorica.</td>
<td>300</td>
<td>Primary incentive at USD 12.70; secondary incentive at USD 6.35.</td>
<td>dried blood spots to test for HIV, HVB, HVC</td>
<td>30-minute, ACASI</td>
<td>Fall 2006</td>
<td>Test results offered on site; pre and post test counseling</td>
</tr>
<tr>
<td>St Vincent &amp; Grenadines (SVG), Eastern Caribbean</td>
<td>Men who have sex with men; males who had manual, oral or anal sex with at least one other male in past six months; aged 15-49 years old; living or working in SVG.</td>
<td>175</td>
<td>Primary incentive: gift bag of condoms, condom pouches, health materials; secondary incentive at USD 9.40.</td>
<td>oral specimen to test for HIV</td>
<td>45-minute, face-to-face</td>
<td>Fall 2006</td>
<td>Participant referred to local clinic for further testing and test results</td>
</tr>
</tbody>
</table>
Table 2. Overview of formative research conducted by each country

<table>
<thead>
<tr>
<th>Country</th>
<th>Methods</th>
<th>Interviewer information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Banja Luka, Bosnia &amp; Herzegovina</strong></td>
<td>In-depth interviews: None, Focus group discussions: Six IDUs recently enrolled in treatment (1)</td>
<td>Observation of IDUs and locations where IDUs and former IDUs spend time Interviews conducted by a trained interviewer in Serbo-Croatian</td>
</tr>
<tr>
<td>Bangkok, Thailand</td>
<td>13 in-depth interviews with FSWs</td>
<td>None, Observation of street-based FSWs, Interviews were conducted by trained Thai interviewers</td>
</tr>
<tr>
<td>Podgorica, Montenegro</td>
<td>4 in-depth interviews with FSWs</td>
<td>None, Observation visits to two brothels; few known visible venues were known, Interviews conducted by a trained interviewer in Serbo-Croatian</td>
</tr>
<tr>
<td>St Vincent &amp; Grenadines (SVG), Eastern Caribbean</td>
<td>2 in-depth interviews with MSM</td>
<td>None, No known visible venue was available through which to observe MSM, trained interviewer in English</td>
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Table 3. Respondent driven sampling-specific formative research questions

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<th>DOMAIN</th>
<th>QUESTIONS</th>
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<tr>
<td>1. Network Properties</td>
<td>Do target population members (TPMs) form a social network? <strong>Do you know or spend time with other TPMs?</strong></td>
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<td></td>
<td>Do the TPMs have large degree? (This question is tied to the survey eligibility criteria) <strong>In a survey of male current drug injectors, ≥18 years, living in city A, ask:</strong> How many men do you know who also know you, they currently inject drugs, they are ≥18 years, they live in city A? How many of these men have you seen in the past month?</td>
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<td></td>
<td>Do the TPMs form diverse social network ties? <strong>Please tell me about how your TPM friends and acquaintances interact with each other (What activities do they do together?)</strong> Do TPMs go out together when they are not working/injecting?</td>
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<td></td>
<td>What is the structure of the social network? Are there cliques and if so, can you find bridges to include them? <strong>If you suspect that TPMs form distinct geographic social networks, ask:</strong> Do you know TPMs who work in/are from other parts of the city? If you suspect that TPMs form distinct social network types, ask: Do you know TPMs who are of a type different from you [e.g., older vs. younger MSM; street vs. bar based FSWs]?</td>
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<tr>
<td>2. Acceptability of RDS</td>
<td>Are TPMs willing to participate in an RDS survey? <strong>Would you (or your peers) be willing to participate in this survey? Why or why not?</strong> What seems most/least interesting about this survey? Would you be willing to recruit your peers into this survey? How many coupons out of three could you give to your peers that they would actually redeem? What might prevent your peers from participating in the survey? Will you (or your peers) participate if the survey includes HIV/STI tests? How would you encourage a friend to join the study? Especially one who is reluctant?</td>
</tr>
<tr>
<td>3. Seed Selection</td>
<td>How do we find good seeds? <strong>Can you think of any TPMs who would make good seeds (describe seeds)?</strong></td>
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<td></td>
<td>If there are cliques can your seeds access bridges to include them? <strong>Do you know different types of TPMs (e.g., who are diverse in age, income, risk, etc.)?</strong> What would be the best way to locate TPMs to be seeds for our survey? Are there NGOs or other groups that work with TPMs? Have other outreach programs used TPMs to contact other TPMs? Can you help us contact TPMs?</td>
</tr>
<tr>
<td>4. Survey Logistics</td>
<td>Incentive: What is the appropriate incentive given the target population and country context? <strong>Do you think ____ (local currency or item of monetary value) is sufficient to encourage TPMs to participate in a survey?</strong> About how much would transport cost to get to the survey site?</td>
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</table>
| Survey logistics: | What hours/days are most convenient for TPMs to participate in a survey?  
| During which hours and days and under which circumstances would TPMs participate in a survey? | Is it convenient for TPMs to get around in this city?  
| How can TPMs get to the survey site? | Is it easy for TPMs to get here on public transport?  
| Do you think TPMs are willing to be interviewed at the same survey site during the same hours? ^1 | What type of survey site would be most comfortable for TPMs to go to? |
| **Staffing:** Who are appropriate staff and when can they work? | Do you prefer men, women, transgender as staff during the survey?  
| Describe the type of person with whom you would feel most comfortable answering personal questions? | Is there a local NGO that you know of with people willing to work in this survey? |
| **Coupon design:** How should the coupon be designed? | Do most of your peers read?  
| What colors are appropriate for the coupon? | Coupons are about the size of ____ , do you think they should be smaller or larger?  
| What kinds of information should be included on the coupons? | Do you think a map on the coupon is helpful for finding the survey site? |

^1 This is important if you are conducting simultaneous surveys.