***Note to conference organizers:*** *I have submitted this abstract to the panel 1905 Obtaining data on special populations: survey techniques and sampling methodologies for developing countries**,** but the same paper could also be presented in panel 1904 on Measuring Hard-to-count Populations and Sensitive Issues. I could also present on the ethical ramifications of using respondent-driven sampling in HIV research to the panel 1402 on Ethical Issues in Demographic Research – but the focus of the paper/presentation would be different. Thank you.*

To understand the dynamics of HIV transmission in countries where HIV prevalence is low, such as those in the Middle East region, it is essential to conduct research on populations at high risk of HIV transmission. However, often these same populations are stigmatized, do not access services and often are engaged in behaviors that are considered illegal. They are therefore very difficult to reach and there is typically no sampling frame from which to sample them.

In recent years, new sampling methodologies have been developed to overcome some of these constraints. One such method is Time-Location Sampling (TLS) whereby populations groups to be sampled are "mapped" in terms of their location and the times at which they frequent these locations and a sampling frame is drawn up from this mapping. An alternative method, and one widely used for reaching hidden populations not in the public domain, is Respondent-Driven Sampling (RDS), a chain-referral method. The main principle behind RDS is that it is led by "peers" or members of the same groups being sampled. Sampling begins with "seeds" selected on a non-randomized basis, and then proceeds in "waves" whereby the first wave would be those referred by the seeds from their social networks, the second wave would be those recruited by the first-wave participants and so on. Developed initially in the United States as a method for reaching injecting drug users, the method is now being widely adopted in developing countries in HIV prevention research among a range of vulnerable groups as well as in other areas of public health research. RDS has now been used in more than 30 countries.

The Middle East and North Africa region has a low estimated prevalence of HIV/AIDS, at 0.3 percent of adults or about 380,000 adults. In Lebanon, adult prevalence is estimated at less than 0.1%. As in the region as a whole, however, HIV/AIDS in Lebanon tends to be under-reported due to the limitations of existing surveillance, the lack, until recently, of accessible voluntary counseling and testing services, and high levels of stigma surrounding infection with HIV. In Lebanon, as in many other countries of the Middle East, however, individuals at highest risk for HIV are not only hidden but engage in behaviors that are deemed illegal.

We conducted an RDS study in Lebanon whose primary objective study was to develop estimates of HIV prevalence among three at risk populations, namely female sex workers, injecting drug users and men who have sex with men. In addition, the study aimed to establish prevalence rates for Hepatitis C among IDUs, and co-infection with Hepatitis C and Hepatitis B for those found to be HIV-positive. The behavioral survey focused on risk behaviors as well as the socio-demographic background of participants and knowledge, attitudes and beliefs about HIV. The study team in Lebanon consisted of

researchers at a university and staff-members from 6 community-based NGOs that cater to the study populations.

A number of challenges emerged in the conduct of the RDS study in Lebanon of both a methodological and ethical nature. On the methodological front, accessing populations is the first difficulty. Ministries of Health in the region are only beginning to interact with populations engaged in illegal activities as part of their AIDS programs. As a study team, we decided to depend on NGOs serving the at-risk groups. However, this strategy faced a number of constraints including the fact that these NGOs – like most in the Middle East region – do not do full outreach to their populations and therefore do not have full knowledge of or access to them. Moreover, it was difficult to convey the importance of the RDS sampling methodology to NGOs whose personnel typically lack a research background. Another methodological issue concerned the challenges of doing an HIV test in field settings and providing counseling and test results to individuals who do not regularly use services. Finally, political instability and intermittent explosions in Lebanon at the time the survey was conducted posed challenges.

RDS also raises many ethical dilemmas and as a team we confronted a number of these. As a method which provides incentive payments to both those who complete the survey and HIV test, as well as those who recruit others to the study, many ethical issues arise around the amount and sequencing of payments. Achieving informed consent among such illegal and stigmatized groups including injecting drug users is often difficult. Finally ethical issues emerge over peer recruitment within networks, such as potential misrepresentation of the aims of the study and its remuneration for participation as well as the risk of potential coercion by peer recruiters.

The presentation will argue that there is a need for qualitative research to complement quantitative research both in terms of gaining a greater understanding of the dynamics of HIV transmission as a whole but also for ethical reasons. We therefore recommend that formative research be conducted to inform sampling methodologies such as RDS, and that in parallel qualitative research on the experience of research subjects be conducted to avoid potential ethical violations. Finally, qualitative research is needed to understand the perceptions of individuals within these hard to reach populations both of their own HIV risk and of needed services.