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# Integrated behavioral and biological assessment: methodological issues in social and behavioral research

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**Abstract.** The IBBA round 1 was the first large-scale probability sample survey in India that included both behavioral and biological indicators among populations most at risk of HIV transmission. The survey was conducted in six endemic states: Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland and among four segments of the National Highways. The IBBA collected data on prevalence of HIV and sexually transmitted infections, HIV risk behaviour and exposure to intervention programs, in a total of more than 25,000 respondents, over a 19 month period between November 2005 and June 2007, across 29 districts in India where Avahan program for these high risk groups were implemented. The survey was implemented by the respective state Indian Council of Medical Research institutes except in Karnataka where Karnataka Health Promotion Trust was responsible for IBBA. Methodological challenges related to social and behavioral areas faced during the implementation of IBBA in various areas like co-ordination of activities and proposed time line, identification and sampling of the target groups, establishment and feed back from the community board members, proper selection and setting up of temporary clinics, maintenance of quality control for both biological and behavioral data and how these challenges were handled are discussed in this paper.

Key words: IBBA, methodological challenges, social and behavioral aspects, India

## 1. Introduction

India had an estimated 2.31 million persons living with human immunodeficiency virus (HIV) in 2007 according to the National AIDS Control Organization (NACO) and the Joint United Nations Programme on HIV/ AIDS (UNAIDS). While the prevalence of HIV in India varies in different parts of the country, geographic pockets of high prevalence have been identified through the National HIV Sentinel Surveillance. More

recently it has been established that the pattern of HIV epidemic in India is one of the multiple concentrated epidemics across the country. Hard to reach populations such as Men having sex with men (MSM) and intra-venous drug users (IDUs) and other high risk groups such as Female sex workers (FSWs) are the main affected groups in India, with sexual route being the main mode of transmission in the country (1). Monitoring the risk behaviors and prevalence of both HIV and sexually transmitted infections (STIs) among these high risk groups becomes very important both from the point of surveillance as well as programmatically for bringing about changes in high risk sexual behaviors. The first generation behavioral surveillance (2-5) provided a means of measuring risk behaviors among these hard to reach groups. More recently, second generation surveillance methods introduced the collection of

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biological samples for testing HIV and or STIs adding to the power of these surveillance and monitoring systems (1).

In 2003, the Bill and Melinda Gates Foundation (BMGF) implemented a large scale HIV prevention program in India, Avahan - the India AIDS Initiative, to implement a large scale prevention program among high risk groups such as FSWs, MSM, Transgenders (Hijra/Aravani), Injecting drug users (IDUs) and bridge groups such as clients of FSW in the six high prevalence states in India and truckers, along national highway segments across the country. As part of the larger evaluation framework of the Avahan program in India, multiple rounds of cross sectional surveys called Integrated Behavioral and Biological Assessments (IBBA) were planned to be conducted among all the high risk groups, with the objective of providing trend data for measuring the major outcomes of Avahan program, to help provide estimates of the sizes of populations targeted by the program and make available information that could be used for modeling the transmission dynamics to show the impact of the program.

This paper presents the details of methodological issues faced while implementing this second generation of behavioral and biological surveillance surveys, one of the first and largest conducted in India. This paper aims to highlight the key social and behavioral challenges faced during implementation of IBBA among the hard to reach and high risk groups, how these were handled and the insights gained for informing future such surveys.

## **2. Material and methods**

The first round of IBBA was implemented as a cross sectional survey using probability sampling methods for high risk groups: FSWs, MSM, Transgenders (Hijra/Aravani), IDUs and other bridge groups such as clients of FSW and Truck drivers. IBBA was conducted across 29 selected districts in India, where Avahan program for these high risk groups was implemented. The first round of surveys were carried out over a 19 month period between November 2005 and June 2007 in six endemic states: Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland and among four segments of the National Highways, having different sampling methods, questionnaires and languages (1). In each state a different Indian Council of Medical Research (ICMR) institute implemented the surveys except in Karnataka where Karnataka Health Promotion Trust (KHPT) was the state implementing centre. Overall technical support

for the IBBA was provided by Family Health International (FHI).

In order to produce a representative sample at the district level, the IBBA used a two stage cluster sampling procedure; in the first stage, clusters were selected using probability proportion to size (PPS) and in the second stage respondents were selected by simple random sampling. Conventional cluster sampling was used for sampling FSWs found at fixed locations; while time location cluster sampling (TLCS) was used for sampling mobile populations such as street based FSWs, MSM, Transgenders (Hijra/Aravani), and Clients of FSW. Respondent driven sampling (RDS) was the method used for sampling hard to reach/hidden populations such as IDUs (6).

### *2. 1. Ethical issues and consent process*

Considering the sensitive nature of the study, all efforts were taken to ensure safety, confidentiality, privacy, autonomy and protection of the participants. Ethical clearances were obtained from Protection of Human Subjects' Committee (PHSC) of FHI and at state level, by ethics committees of all implementing centres like ICMR Institutes. Each participant was explained about the need and aims of the study, procedure, risks and benefits, voluntary nature and all ethical issues involved, to decide about their willingness to participate in the study. Among the willing participants, written or witnessed informed consent was obtained individually, before proceeding with data collection.

### *2. 2. Instruments, Training and Data collection*

The questionnaires for each survey group included questions on profile characteristics, sexual risk behaviors, condom use with different partner types, mobility and migration, knowledge of STI / HIV and risk perception for HIV and exposure to different program / interventions. Biological samples (blood and urine, and genital swabs - if genital ulcers were reported) were collected from all participants in private settings, assuring confidentiality and anonymity without any identifying details.

In each state a local private research agency was hired for conducting field work. A comprehensive training was provided to the local field teams, on the various survey methodologies. Multiple levels of monitoring mechanisms took place throughout the survey by the state ICMR teams, by central teams from ICMR and FHI.

### *2. 3. Benefits to participants*

A major benefit to the participants in the IBBA was the access to medical examination and treatment by a doctor at the time of the survey. Additionally, a system of referrals to existing networks of clinics providing STI treatment was established during the survey in each district and participating respondents were given referrals to these clinics to get the syphilis test results, and treatment, if found positive.

## **3. Discussion**

The results of the IBBA round 1 which were already published (7) are not presented in this article. The discussion focuses mainly on key methodological issues related to social and behavioral aspects of the implementation of IBBA round 1.

The massive scale of implementing the IBBA meant significant amount of planning, coordination and timing across the states and nationally for proper implementation.

### *3. 1. Coordination and Timing*

IBBA implementation involved different layers of coordination between multiple implementing partners, both centrally and within each state, including state ICMR institutes, Avahan, FHI, the research agencies, the Avahan state lead partners, the NGOs working with Avahan, and the key populations. Facilitating and harmonizing the functioning of these varied institutions and communities with respect to the IBBA, each with its own infrastructure and norms, was an enormous challenge to timely implementation. Although the goal was to implement the IBBA simultaneously in all groups with standardized methods, tools, and SOPs, the diversity across districts and states, and the fact that the IBBA was implemented by different partners in each place, made that difficult. Still, the advantage of the staggered implementation was that lessons learned in earlier surveys could be incorporated from one district to another, as the IBBA evolved.

### *3. 2. Pre-survey assessments, mapping and sampling frame development*

IBBA aimed at obtaining representative sample for all groups at the district level. Further with the goal to have a probability based sampling approach it was required that a complete universe or sampling frame of all hot spots or sites where the high risk activity are located be identified,

mapped and listed. IBBA districts differed in terms of the typology and patterns of sex work and therefore some levels of pre-survey assessments were required at the district level to finalize the sampling approach.

Efforts were made to contact the centres conducting intervention programs in the districts and with their help complete listing of hotspots and sex venues in each district were mapped as a rapid exercise. The intention was to map the majority of sites in both urban and rural areas having a significant number of FSW and MSM population, which was determined based on qualitative information collected locally in each district. During the rapid mapping exercise detailed data on, hot spots, their operation hours including peak and lean days and hours, the number of high risk group members who would be available at various times of the day, were collected with the help of local key informants as well as community consultants (FSWs and MSM). This was also a very sensitive part of the survey as it covered identification of correct key informants and volunteers from the respective group who helped to get these sensitive details. Because of reasons like police raids, rowdism and local problems some of the hotspots which were initially found active were closed and they became dead sites at the time of survey. The new sites that might have appeared during the period were probably missed. However, it was difficult to estimate how it would impact the representativeness of the sample.

### *3. 3. Methodological Challenges*

The sensitive nature of the target groups and the subject matter of the IBBA required thorough sensitization, careful planning and vigilant monitoring of all survey staff. Added to that effort were the challenges encountered in using a new methodology, respondent driven sampling, in several locations, as well as reaching consensus on a methodology for sampling clients of FSWs that was acceptable to all partners.

### *3. 4. Respondent Driven Sampling*

RDS is a method of chain-referral sampling; this depends on drawing recruits from the personal networks of its initial (seeds) and subsequent respondents. It employs a dual system of structured compensation: one for the respondent being interviewed and another for recruiting peers to be interviewed (6). This method was used (8) for populations in which the pre-survey assessment suggested that the

population did not congregate at identifiable locations or the proportion of members accessible at identifiable locations was insufficient to represent larger group and that the population was sufficiently networked. This included all IDU groups, one FSW group in Nagaland and three FSW groups in Maharashtra. The methodological considerations in the areas like seed selection, seed addition and duration of field work, leading to low or poor participation of the respondents were corrected by adding seeds when recruitment was low, when new data collection centres were opened or when the recruitment became unbalanced in terms of the type of respondents or when existing chains were not productive. Based on the experience in bar girls survey in Thane districts qualitative research methodology was employed to understand the barriers to participation. Changes in the eligibility criteria for enrollment and increase in the amount of compensation resulted in successful completion of survey among bar girls in Mumbai. A separate sample of "all FSWs" using RDS was also conducted in Mumbai to try to capture some of the less visible/non-venue-based sex workers. This survey captured a large segment of call girls, as well as many home and bar-based sex workers. An attempt was made to understand the linkages and network between the types of FSWs.

### *3. 5. Sampling of client's of FSWs*

Male clients of FSW are one of the most hard to reach sample groups. During IBBA different sampling methods were piloted to arrive at a best method that would also be a probability based method. We first attempted to sample clients from venues where FSWs entertain clients. A large proportion of IBBA districts included those whose typology of sex work was largely public based solicitation and less home or brothel based. List of venues were not readily available for the majority of districts. During the pilot stage, a mapping effort was taken up to identify all the sex venues, brothels, lodges, homes etc. This revealed that a significant proportion of FSWs entertained their clients in places such as rented homes, homes of their friends, vehicles and public places, which could not be mapped. The main limitation of this method was that it was not feasible to map exhaustively such locations in the districts to cover the entire geographic area. There were also practical problem associated with sampling clients from homes of FSWs. In sex venues that were homes, recruitment of clients was found to be too dependent on sex workers

and often an unbiased selection could not be assured and further taking the help of the FSW in recruitment could lead to harm to the FSW and or adversely affect her sex work business.

Sampling clients at places where FSWs solicit their clients allowed for widest coverage of sites where transactional sex occurs. The main challenge in these sites was identification of clients, recruitment and having to determine the number of clients in the site for calculation of selection probabilities. To overcome this difficulty a triangulation method for identifying clients was used, where help was taken from FSWs, pimps, and other key informants at the site to identify potential clients. Refusal to accept visiting a sex worker was high and therefore the final result was that a large number of potential clients had to be seen to achieve the final sample. Since clients are considered to be a mobile group, TLCS approach was used, to ensure capture of a representative sample of male clients in a given geographic area. While this does not represent all clients of sex workers, it does represent a sizable subset that was feasible to sample, given the challenges of sampling this population, i.e. the difficulties in identifying clients. Excluded from this sample were clients of lodge and home-based sex workers, since those venues were generally not included in the sampling frame of sex solicitation points, but were rather considered as sex sites. Clients of service bar based sex workers were also not included because of sampling challenges. Another sensitive issue was that urine had to be collected from these clients before having sex with the FSWs as it would interfere with the laboratory results. This required more explanation from the survey team for recruitment of clients, better understanding from the clients, risk of loss of these clients for the FSWs and chances of added refusals from other clients.

### *3. 6. Surveys among Aravanis / Hijra community*

Another unique aspect of the IBBA was to cover a different hard to reach group, Transgender or Aravani / Hijra as they are referred to in India. This group was planned to be covered in two states, in Tamil Nadu and Maharashtra, where they are estimated to be in larger numbers. In Tamil Nadu, a combined sample of Transgenders was planned across the five districts where IBBA was conducted. The pre-survey assessments and community preparation served to be very important for successful completion of the Aravani survey in Tamil Nadu. During the pre-survey assessments

it was found that there were significant proportion of Aravanis who solicit from their homes in all districts, which would make it difficult to sample them from public places. Further, among those who solicited in public places, we found that Aravanis stay for very short time in hot spots, due to stigma and fear of police, a potential problem for sampling. The detailed information on timing, collected during the mapping exercise served very useful for successful recruitment from public places.

Community preparation among Aravanis involved meeting with all the Jamat leaders or gurus of Aravanis, without whose support and cooperation it would not have been possible for the survey to be conducted. Aravani gurus in each district was identified and met with and informed about the nature of IBBA. Meetings were also held with Aravani-community members, similar to other groups, to inform about the nature and process of IBBA.

Whereas in Mumbai, in spite of extensive community preparations, the transgender/Hijra survey could not be completed. The movement between the sites of the respondents was very high and could not trace/ track the Hijras and count them correctly even with the help of Community Liaison person. In addition to the NGO's non-support to IBBA, there were other reported reasons for their high refusals rates like 'do not want to loose customers by their participation in the IBBA as they would be getting identified' or were seeking care from NGO. Due to these reasons transgender survey could not be completed in Mumbai and Community Advisory Boards (CABs) and Community Monitoring Boards (CMBs) meetings were concurred for concluding the survey.

### *3. 7. Setting up of temporary clinics*

In order to ensure least disturbance to the respondent's activities and for better compliance we set up temporary sites close to the recruitment sites. A number of obstacles were overcome including difficulty in getting places for the clinics, as the owners of the places were unwilling to give space for the sensitive work especially when socially stigmatized population would be visiting, particularly in a residential area. This was overcome by establishing IBBA clinics in government hospitals wherever possible, rented residential places, lodges, marriage halls, shacks / huts or sometimes in the homes of sex workers (especially during surveys

for brothel based sex workers) with prior cooperation.

Biological specimen collection was a challenging work in this survey as it involved blood drawing and genital swab collection (wherever genital ulcers were reported) in addition to urine collection. There would be a possibility of under reporting of respondents having genital ulcer for its sensitive nature related to examination and ulcer swab collection. This was also addressed by the team for not missing many specimens. All the collected biological specimens were transported to district laboratories and stored safely until time of testing or transfer to the State or Central labs, while maintaining under cold-chain conditions. This was specially challenging in areas such as those of the North-East, where access was limited and terrain was rough for traveling. Local insurgency also made movement difficult. Poor infrastructure / facilities, such as electricity, telephone, internet, refrigeration, etc. at the district level, also presented a number of implementation challenges which were solved by handling the problems locally.

### *3. 8. Community preparation*

Given the sensitive nature of the high risk groups covered and information proposed to be collected, preparation of the communities of high risk groups was taken up as an important part of the survey activity early on. It was realized that without involving the risk groups, it would be difficult to reach these populations or gain their trust for ensuring participation. Therefore in each IBBA district community preparation activities were taken up by involving the existing NGOs implementing programs with high risk groups, their staff, outreach workers, district level officials, high risk group members themselves and the gate keepers such as pimps, madams, police and other community leaders. Involvement was sought by formation of a CABs and CMBs in each district. CABs included members such as officials, community leaders and other influential persons who could help and guide the survey teams, to suggest mechanisms for avoiding adverse events and to help address problems as and when they arose in the community. The CMB was represented by the members of the high risk populations who visited the areas where survey was implemented and their main role was to ensure that respondents' interests were protected, they were treated well

by survey team members and that autonomy and confidentiality of participants were not violated.

Ultimately, during community preparation activities all efforts were taken to make all the stakeholders aware of the basics of the survey, listen to community concerns, and minimize any harm or threats to the communities as a result of IBBA. These community preparation activities served well in all districts to limit the refusal for participation in the survey and minimized negative backlash due to survey from community (as it involved collecting sensitive information and blood samples). The process of community preparation helped the field teams to get valuable inputs for successful implementation, including helping field investigators to be more sensitive and understand better the pulse of the target community, their expectations and their concerns. Community preparation activities also helped the field team to learn about community's apprehensions and alleviate them, methods of approaching community members, importance of dress code, body language, making eye contact, about police activities, and terminologies used by community members to be used during interviews to build better rapport with respondents and getting more accurate information during interviews. During these meetings, role-plays were also held between the survey team members and the community to enable a thorough understanding of the IBBA and develop a comfortable feeling about the IBBA by both the survey team and the community. Community preparation was therefore a very important exercise to bring the IBBA team and the community together in order to plan and conduct the IBBA effectively.

### 3. 9. *Lessons learnt*

There were numerous lessons learnt from the implementation of round I of IBBA for conducting social and behavioral research. Given the sheer magnitude of the survey, it was found that proper planning and well coordinated action from central to the state teams was identified to be very important for timely rollout and completion of surveys. Having detailed technical guidelines, SOPs and manuals for behavioral and biological components were an important strength for ensuring methodological rigor of the surveys. Proper training of the field investigators, laboratory technicians and doctors on the survey procedures and sensitizing them dealing with high risk groups was very important for maintaining the cooperation levels of participants as well as quality of data collected. Very

importantly, the preparation of the community and involving them and the local stakeholders (interventions) without introducing significant bias was a key to the successful completion of surveys in all states. Finally, the learning from round I of IBBA provide valuable insights for planning and collecting sensitive information from vulnerable or high risk groups in the country at a district, state and national level.

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