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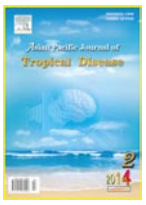

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Optimizing the implementation of integrated biological and behavioural surveillance surveys of HIV in resource limited settings-lessons from Nepal

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ABSTRACT

Objective: To discuss the basic standards for HIV related integrated biological and behavioural surveillance (IBBS) survey implementation, specific challenges of survey management, and to propose brief practical guidelines for management of IBBS surveys in resource limited setting.
Methods: Two methods were used to address our study objectives: (a) a narrative review of the literature and (b) our experience as participant observer when working on IBBS survey management between July 2012 and January 2013 in Nepal.
Results: In Nepal, IBBS surveys are conducted among key populations at higher risk of HIV such as people who inject drugs, men who have sex with men, female sex workers, seasonal male labour migrants and truckers (proxy for clients of female sex workers). The involvement of different institutions, people, and procedures makes IBBS survey management-including planning, implementation, sharing of findings and possible uses of survey findings-complicated to perform. In addition, basic survey methods and techniques including respondent driven sampling and two stage cluster sampling, are sometimes not properly performed in practice.
Conclusions: This study showed that field implementation of some standards methods such as respondent driven sampling and cluster sampling for HIV related estimate or trends used for IBBS survey could be improved. This paper described lessons learnt and may be used as a guiding reference to improve and evaluate IBBS surveys in resource-poor settings also outside of Nepal.

1. Introduction

Integrated biological and behavioural surveillance (IBBS) surveys, one key component of second generation HIV surveillance, have been used in many concentrated epidemic contexts. More recently, IBBS survey has also been recommended in generalized epidemic settings[1]. As the HIV incidence has declined up to 50% in 26 countries over the last decade[2], there is a need for more focused and valid second generation surveillance approaches including community led IBBS surveys to understand the dynamics and drivers of micro-epidemics[3,4].

In Nepal, repeated cross-sectional IBBS surveys make up the major source of information for HIV prevalence and risk behavioural, trend dynamics, response monitoring and evidence-based interventions aimed to curb new HIV infections in the country. Nepal is experiencing a concentrated HIV epidemic defined as aseroprevalence that is below 1% among pregnant women in urban areas, but is consistently higher than 5% in at least one subpopulation. The key subpopulations at higher risk of HIV in Nepal are people who inject drugs (PWID), female sex workers (FSW), men who have sex with men (MSM) and transgender people, and, seasonal male labour migrants (MLM), particularly those migrating between Nepal and higher HIV prevalence areas in India. In 2012, the HIV prevalence among these key populations was very high: 6%, 4%, 2% and 1.3%, among PWID, MSM and transgender, FSW and MLM, respectively[5].

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In the early 1990s, a national HIV surveillance system was established in Nepal to monitor the HIV epidemic and to inform evidence-based HIV prevention efforts[6]. Since then, IBBS surveys have been conducted every two/three years among key populations at higher risk of HIV in identified three epidemic zones to collect information on socio-demographics and biological markers to assess the prevalence of HIV and other sexually transmitted infections (STI), behavioural information (condom use, number of sex partners, needle sharing behaviours). The epidemic zones are based on different distributions of key populations at risk, mobility links and HIV risk behavior.

The key subpopulations at higher risk of HIV (especially MSM, PWID and FSW) in Nepal frequently suffer from discrimination and marginalization, and their behaviors such as drug use or sex work are often illegal, making it even harder to reach them. The existing social stigma and criminalization of these behaviors impede the development of sampling frame for random recruitment of key subpopulations in HIV surveillance surveys such as IBBS. Unique sampling technique such as respondent driven sampling (RDS)[7], a network based chain-referral sampling method, has successfully been used to recruit and calculate unbiased population estimates of hidden marginalized group both in high income and resource constrained settings[8,9]. RDS yields a representative sample and estimates unbiased population parameters when all its methodological and theoretical requirements are fulfilled[7-9]. In Nepal, RDS has been used in IBBS surveys to recruit the MSM and PWID in Kathmandu and Pokhara valley.

HIV related biological and behavioral surveillance surveys have been widely implemented in resource poor health systems in different cultural context[10-12], resulting in estimates of varying quality albeit using similar survey processes and methods[13]. There is a growing evidence that IBBS surveys that use RDS to recuit hidden populations have failed to adhere to the rigorous implementation and analysis requirements, and Nepal is no exception[14,15]. Evidence also suggests that failing to fulfill RDS assumptions may result in biased estimate[16,17]. Issues of assumptions of violation of other sampling techniques to recuit hidden populations, such as two-stage cluster sampling has been inadequately documented in published studies.

Few have described the general methodology framework for IBBS survey management[18,19], but the level of coordination between and within institutions and the competence to manage surveillance surveys differs greatly between settings, and the management process therefore needs to be locally adapted[13,20]. The objectives of this study is to discuss the basic standards for IBBS survey implementation, to identify specific challenges in relation to survey implementation, and to propose a set of brief practical guidelines for management of IBBS surveys in a resource-limited settings such as Nepal.

2. Materials and methods

We reviewed the relevant Nepalese literatures and performed a participant observation including the development and piloting of a checklist/field guideline[21] during the 2012/13 rounds of IBBS survey implementation and management for HIV surveillance, across 32 districts in Nepal. Several co-authors have previous experience from coordinating and implementing surveys including IBBS surveys. In this paper, the term "survey population" or "target population" is used to represent PWID, MSM, FSW and seasonal male labour migrants.

2.1. Narrative review of the literature

We undertook a narrative review of the relevant literature (Table 1) aiming to reveal weaknesses and contradictions in a field of IBBS surveys in Nepal[22]. This study not only aims for problem identification but also proposes some tentative solutions to the problems related to the IBBS survey management. For our literature review, all the relevant literatures including previous rounds of IBBS survey reports of Nepal were extracted from the National AIDS Research Library of National Centre for AIDS and STD Control (NCASC), which is a government apex body that regulates the HIV prevention efforts in Nepal.

2.2. Participant observation in IBBS management and implementation

We also used participant observation to learn through involvement in, the day-to-day/routine activities of IBBS management and implementation[21]. The advantage of using participant observation is that it helps researchers to gain a holistic understanding of the phenomena under study and to generate future research hypothesis. Three co-authors (KD, DKK, BO), all members of the national surveillance supportive monitoring group, in Nepal, were involved as participant observers throughout the IBBS survey conducted in 32 districts of Nepal between July 2012 and January 2013. Except senior officials of NCASC, the co-authors did not inform other members or institutions involved in the management of the IBBS survey about their intention to conduct participant observation research. During survey period, the formal task of the co-authors (KD, DKK, BO) was to monitor and ensure the quality or standards of IBBS surveys planning and implementation at the field, and they visited multiple survey sites at district level. Field notes were taken throughout the course of the study covering observations as well as casual conversation with different individuals involved in implementation and management of IBBS surveys at field level.

We also used standard checklist/field guideline to guide

Table 1

IBBS surveys conducted in Nepal 1999–2012.

Key populations at higher risk of HIV	Survey sites (districts)	Survey years	Sampling technique	Sample size[†]
FSW	Kathmandu valley (Kathmandu, Bhaktapur and Lalitpur districts)	2004, 2006, 2008, 2011[**]	Two stage cluster sampling	500
	Pokhara valley	2004, 2006, 2008, 2011[**]	Two stage cluster sampling	200
	16 Terai Highway Districts	1999, 2003, 2006, 2009, 2012	Two stage cluster sampling	400
	6 Terai Highway Districts	2004, 2006, 2009, 2012	Two stage cluster sampling	200
PWID	Kathmandu valley	2002, 2005, 2007, 2009, 2011[#]	RDS	300
	Pokhara valley	2003, 2005, 2007, 2009, 2011[##]	RDS	300
	East terai districts	2003[*], 2005[*], 2007, 2009, 2012	Two stage cluster sampling	345
	West to far west terai districts	2005[*], 2007, 2009, 2012	Two stage cluster sampling	300
Truckers (proxy of clients of FSW)	22 Terai Highway Districts	1999, 2003, 2006, 2009	Two stage cluster sampling	400
MSM/transgender people	Kathmandu valley	2004, 2007, 2009, 2012	RDS	400
Male labour migrants	West to far western region	2001, 2006, 2008, 2012	Two stage cluster sampling	360
	Mid and far western region	2010, 2012	Two stage cluster sampling	360
Wives of labour migrants	Far western region	2002, 2008, 2010[###]	Two stage cluster sampling	600

[†]: Sample size of the IBBS survey is planned to detect the changes (10%–15%) in prevalence of HIV and key risk behaviors among the survey population. [*]: RDS was used in this survey round. [**]: From this survey round, sample size of FSW in Pokhara valley was 345; sample size of FSW in Kathmandu valley was 593. [#]: Sample size of 340 was used in Kathmandu valley. [##]: In this survey round, the sample size was 345 in Pokhara valley. [###]: IBBS survey among wives of labour migrants is discontinued as of 2010. HIV prevalence among them to be monitored through prevention of mother to child transmission of HIV data.

the monitoring of all the major aspects of IBBS survey implementation. The checklist covers the issue of survey design including sampling technique, survey set-up, interview and counselling process, basic lab and clinical aspects of IBBS survey. The checklist was piloted at sit-in observations, record reviews and informal staff interviews.

2.3. Standards for the surveillance survey used

In this study, the standards for the surveillance system used are adapted from the U.S. Centers for Disease Control's Guidelines for Evaluating Public Health Surveillance Systems[23]. The attributes of the surveillance system are described to provide an understanding of the basic standards of IBBS surveys, focusing on sensitivity, representativeness, simplicity, flexibility, data quality, acceptability and timeliness. The standards have been categorized into three parts describing their function: 1. Enhance the understanding of an HIV epidemic focusing on a) sensitivity: IBBS survey's ability to monitor trends in risk behaviors and in the prevalence of HIV and other STI, and b) representativeness: generalizability of IBBS survey findings in target populations; 2. Support public health action focusing on a) simplicity: IBBS survey structure and implementation, b) flexibility: the flexibility of the IBBS survey to adapt to the dynamic nature of the HIV epidemics with limited additional time and resources (human and financial), c) data quality: completeness and validity of IBBS survey data, and d) acceptability: degree of involvement and interaction between the survey staff and the community, important for accurate, consistent, complete and timely data; 3. Prompt response to the HIV epidemic, timeliness: on-time evidence-based design and implementation of HIV prevention, treatment, care and support services based on IBBS survey findings and other sources. The challenges faced to meet these standards in the field setting will be discussed below using the IBBS 2012/2013 example from Nepal.

2.4. Trustworthiness

Standard principles-credibility, transferability, dependability and confirmability proposed by Guba were followed to ensure the trustworthiness of the study[24]. Credibility was achieved by using different methods (narrative literature review and participant observer). We also used standard guidelines or checklist to monitor all the major aspects of IBBS survey. The use of guidelines also helped to avoid researcher predispositions and increased the confirmability of the research. Transferability and dependability are ensured by our having described study methods and process in detail, as well as the study context, the study findings and their applicability. Altogether, these practices should help others understand the study context and be able to replicate our research process to evaluate IBBS surveys in other resource-poor settings.

3. Results

3.1. IBBS surveys enhance understanding of HIV epidemic in Nepal

The main objective of IBBS surveys is to track changes in risk behaviours (non-use of condoms and unsafe needle use), in HIV prevalence and other STI (gonorrhoea, syphilis, and chlamydia trachomatis) over time to inform future public health actions. Additional survey variables are described in detail in Table 2. Risk behaviours and their importance for HIV transmission differed markedly between the large regions of Nepal. As shown in Figure 1, commercial sex and injecting drug use were the major drivers of HIV transmission in the Terai Highway Districts (East-West-Far west and in the Pokhara valley), while male-male anal sex, in addition to commercial sex and injecting drug use, is more important

Table 2

Information collected in IBBS surveys in Nepal.

Categories	Variables
General information	Place of birth, current place of residence, duration of stay at current place and previous place of residence
Personal information	Age, ethnicity, educational status, marital status, age at marriage, current living situation, birth history, pregnancy history, knowledge and use of family planning, history of sex work, and income from sex work and other works, sexual orientation
Information on sexual intercourse	Age at first sex, type and number of sex partners, professional background of client/sex partner, number of clients/sex partners in a day, last week or/and last month
Use of condom and information on sex partners	Condom use with different sex partners (steady and one-time)-in the last sex and in the last month, knowledge and use of female condoms (for FSW), access to condoms
Condom accessibility and lubricants	Carry condoms, place to buy condoms and lubricant, duration taken to buy condom and lubricants, preferred place to buy condoms and lubricants
Use of oral and injecting drugs	Types of drugs used, duration of drug use, frequency of drug use, treatment, needle sharing behaviours, access to safe needles
Alcohol use	Ever use of alcohol, types, had alcohol during last sex
Awareness of HIV and AIDS	Knowledge of HIV/AIDS and misconceptions
Promotion of condoms	Heard about different brands of condoms
Exposure to interventions programme	Exposure to outreach and peer-education, use of drop in centre, visited HIV testing and counselling centres and STI services and participation on community awareness events
Sexually transmitted infection	Knowledge and use of services available for sexually transmitted infection, currently experiencing STI symptoms
Psychosocial and structural factors	Housing instability, distress, depression, self-esteem, social support, suicidality, stigma, experience of institutional based discrimination, violence, cross border movement for illicit drug use
Biological (lab testing)	HIV, syphilis, chlamydia trachomotitis and *Neisseria* gonorrhoea test

in the Kathmandu Valley. Previous IBBS surveys have also shown that Nepalese male migrants who visit FSW with a higher HIV prevalence in India, constitute a major route of infection in the far-western hills of Nepal. In the remaining hill districts, all of the aforementioned risk factors exist but to a much lesser extent.

Figure 1. HIV epidemic zones of Nepal.

The following issues need to be addressed to ensure that IBBS surveys accurately track any changes in HIV prevalence and risk behaviours such as ensuring representativeness (adequate participation rate of the survey population), using accurate tools (*e.g.*, survey questionnaire) adapted to the local context, and making efforts to reduce self-report bias (*i.e.* performing the study in a context-sensitive way that enables the study population to report accurate information).

3.1.1. Ensuring representativeness of survey findings

Representativeness is dependent upon the methods used to monitor trends in the surveyed population, and how well these methods perform in that particular setting. Potential biases need to be identified, carefully considered and then addressed throughout the development of sampling frame, selection of the survey population and during data collection[25]. Different data collection methods have been used in IBBS surveys to capture the diverse nature of the target populations surveyed (Table 1). However, the methods used have changed over time, possibly threatening the validity and precision of observed trends. For example, in the early years (2003 and 2005) of HIV surveillance, RDS (described in more detail below) was used, while later on, cluster sampling was used to recruit the same target population (PWID) in the Eastern, West to Far West Terai Highway Districts (Table 1).

3.1.1.1. Two-stage cluster sampling

Two-stage cluster sampling aims to ensure the probability selection of possible survey participants by the selection of clusters using the probability proportional to size method in the first stage, and, in the second stage, random selection of possible survey populations from each selected cluster. For example, a cluster for FSW was defined as a location (dance bar, massage parlor or cabin restaurant) with at least 30 sex workers and therefore, locations with fewer than 30 FSW were theoretically merged with neighboring sex work locations to create a sampling frame for this key population. This sampling method has been used by IBBS surveys to recruit both PWID and FSW in Terai Highway Districts, and MLM in the West to Mid and Far west districts in Nepal (Figure 1). In all surveys, mappings were performed in two steps to develop the sampling frame (group of clusters) from which possible respondents are selected randomly to ensure representativeness of survey findings. Social mapping has been conducted in collaboration with people from the community, service providers and district level

non-governmental organizations (NGOs) to develop sampling frames. The main aim of social mapping is to map areas (clusters) where high HIV risk behaviours occur (sex work, drug use) and for estimating the individuals who could potentially be surveyed in each area.

In Nepal, initial mapping was conducted to gather information about the possible number of survey individuals in each cluster. Second or real mapping was conducted to develop sampling frames of the selected clusters based on probability proportional to size to list possible survey individuals. The second stage is more time-consuming and considered to be the real mapping exercise and because in this stage, field workers visit each cluster and contact possible survey individuals to develop the sampling frame. In the initial mapping, the sampling frame was largely based on the information provided by NGOs (who are involved in providing sexual and reproductive health services to various key populations), local leaders (in the case of male labor migrants), from available secondary literature (Central Bureau of Statistics data in the case of MLM), and sometimes by the survey team itself (when no evidence was available from other sources). Following the second mapping exercise, equal numbers of survey participants from total selected clusters were enrolled to ensure a self-weighted sample. Methodological issues to ensure self-weighted sample are described elsewhere[18].

The main challenge in two stage cluster sampling is to ensure that the measure of size of each cluster in the initial mapping is approximately the same as the measure of size of each cluster in the real mapping, to provide the self-weighted sample[18]. This is a difficult task for many reasons, including the mobile nature of the survey populations and non-existence of high quality secondary information about them.

3.1.1.2. RDS

RDS was specifically designed to reach hard to reach individuals within hidden populations without a sampling frame[26]. RDS has successfully been used to recruit MSM and PWID in IBBS surveys in Kathmandu, and Pokhara valleys. RDS recruitment uses the participants' social networks for recruitment; similarly to snowball sampling, participants are recruited through their peers, but in a controlled monitored way. The strength of RDS is that it produces selection probabilities that enhance its credibility as a probability sampling method. The selection probability is largely based on the size respondents' personal social networks defined as how many persons the survey participant knows who fulfil the inclusion criteria of the survey population and thereby possibly could be invited to the survey. This is usually measured by asking survey participants about how many people they know who fit the survey criteria, and can therefore be subject to self-report bias. The answers of the respondents are then weighted against the size their networks, This has been shown to produce statistically proven unbiased population estimates when the RDS criteria are fulfilled[27,28].

The following network size questions were used in all RDS surveys: (a) How many other MSM do you know who also know you well (knowing someone is defined as being able to contact them, and having had contact with them in the past 12 months); (b) Among those people, please try to estimate their number by age group: <15 years old and >15 years old; (c) How are you related with the person who gave you the coupon for taking part in the study (response category: close friend, friend, sex partner, relative and stranger). During data analysis of RDS survey in 2009, MSM respondents were found to have highly overestimated their personal network size, which leads to substantial differences in HIV prevalence[29].

3.2. IBBS surveys support public health action

The overall operation and management structure of IBBS surveys (described in Figure 2) involves different institutions. Our literature review revealed that the lack of proper documentation of the survey process led to the repetition of the same unintentional errors in repeated rounds of the surveys and is a missed opportunity for improvements. One example of such errors is the highly inconsistent measure of cluster size between initial and real mapping in two stage cluster sampling, another one is the over-estimation of the personal network size when using the RDS method to recruit MSM.

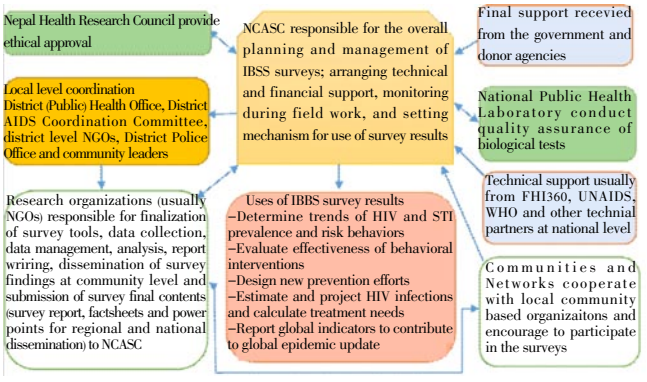

Figure 2. Overall management process of IBBS survey in Nepal, 2012.

A surveillance system should be flexible enough to handle the changing needs of information by population and geographical areas in order to effectively inform public health actions. In the beginning of IBBS survey, RDS was used to recruit PWID in all regions (Kathmandu, Pokhara valley and Terai Highway Districts). After two rounds of IBBS surveys (2003/2005) among PWID in geographically wide east-west Terai Highway Districts of southern Nepal, the survey team realized that one of the major assumptions (one network component or member of the survey population are networked) of RDS was violated[30]. To be more specific, this assumes that all survey respondents are interconnected and this would be violated if survey respondents did not

cross-recruit other respondents (so called bottlenecks) from different survey sites or districts. Figures 3, 4 and 5 provide the evidence of a bottleneck phenomena in one of the survey population (PWID) by home districts or survey site. Based on this evidence, the survey management team of 2005 decided to stop using RDS and switch to cluster sampling to recruit PWID in the Terai Region. Our review found that the possible impact of bottlenecks on the HIV-related estimates among PWID was not properly considered when trends were analysed.

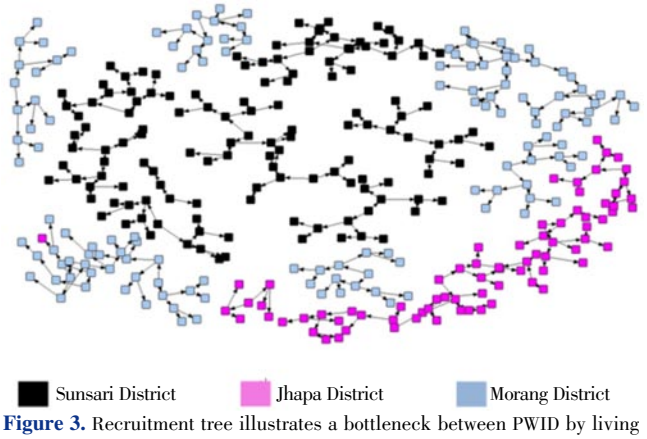

Figure 3. Recruitment tree illustrates a bottleneck between PWID by living districts in eastern Terai highway in 2003.

Note: Each node refers to 1 respondent and recruitment tree showing the only active seed. Figure was developed using NetDraw software (Graph Visualization Software. Harvard: Analytic Technologies).

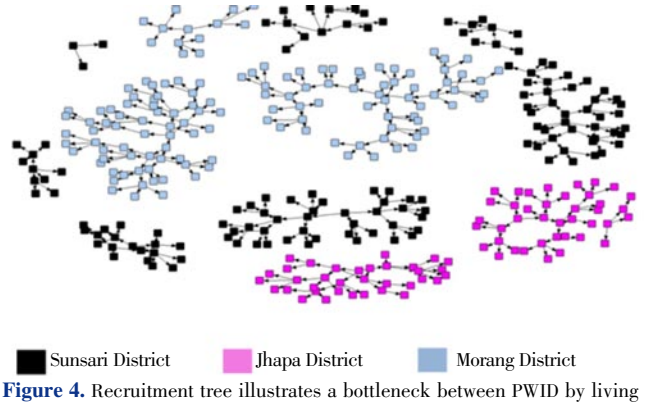

Figure 4. Recruitment tree illustrates a bottleneck between PWID by living districts in eastern Terai highway in 2005.

Note: Each node refers to 1 respondent and recruitment tree showing the only active seed.

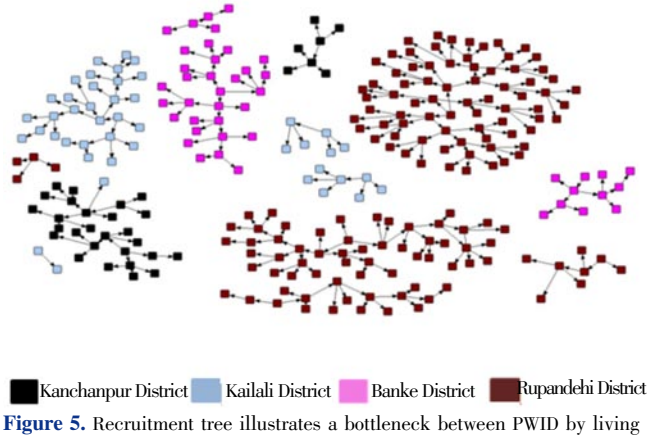

Figure 5. Recruitment tree illustrates a bottleneck between PWID by living districts in West to Far-west Terai highway in 2005.

Note: Each node refers to 1 respondent and recruitment tree showing the only active seed.

Considering the limited epidemiological information about MSM and transgender people in Nepal, the plan is to extend IBBS to include both groups in the Terai Highway Districts (Figure 1) beginning in 2014. Previously, the IBBS survey was limited to the three districts in Kathmandu valley in Nepal. The decision to expand IBBS surveys to new locations was supported by the HIV related information provided by the NGOs working for MSM/transgender people in different districts of Nepal.

Growing but limited evidence suggests that psychosocial health problems interact in a synergistic way to increase HIV and STI related risk behaviour among key populations[31-36]. The high prevalence of discrimination, violence and social rejection among Nepalese MSM/transgender people has bade it clear psychosocial risk factors need to be assessed[31]. Beginning in 2012, the following variables related to psychosocial factors were therefore added to the IBBS survey questionnaire: housing instability, social support, social isolation (family rejection), mental health status (distress and depression) including suicidality, cross border movement for illicit drug use and institutional based discrimination. Extending the questionnaire led to longer interviews, possibly affecting the patience and willingness of the respondents to complete all data collection components (interview and biological sample collection of blood and urine). It takes around 40-50 min to complete the questionnaire through face to face interview followed by 30-40 min for counselling, drawing blood, and obtaining a urine sample and, anal swab,and disseminating lab test results.

3.3. Using IBBS surveys to assist prompt response to HIV epidemic

We observed that some of the key personnel for IBBS surveys in Nepal, especially those involved in financial and program management, do not participate in the planning stages of the IBBS survey management process, which left them unaware of the consequences of delayed survey completion. In the 2012 IBBS survey, delayed in the release of funds to research organizations who had already moved to the survey site increased the number of working days in the field and also influenced on-time dissemination of survey findings. The cost of field work increases with the increasing number of working days in the field, making all delays expensive.

4. Discussion

IBBS surveys provide essential information about HIV dynamics in low-income contexts and contribute to the design of evidence-based prevention efforts. We have used the case of Nepal, comparing previous as well as more recent (2012/13) IBBS surveys to assess planning and implementation challenges that could influence the validity and precision of

reported HIV estimates. Our study show that the involvement of different institutions, people, and procedures in recruiting marginalized and hidden populations makes IBBS survey management-including planning, implementation, sharing of findings and possible uses of survey findings-complicated. Despite a decade-long experience of conducting IBBS surveys, Nepal is still experiencing implementation challenges, but similar problems also occur in other low-income concentrated epidemic settings where similar methodologies are used[37]. Our study findings also suggest that deviation from the standard protocol is common-especially in sampling technique-and rarely accounted for during data analysis, threatening the validity of observed trends of HIV prevalence among vulnerable populations. A systematic review of 123 studies conducted in 28 countries that used RDS to gather HIV related biological and behavioral data, confirms that violation from standard protocol was common during study design, operation and data analysis in different low income countries[14].

4.1. Enhancing the understanding of HIV epidemic

In Nepal, research organizations involved in IBBS survey data collection often lack the wide networks in the survey districts required to successfully enroll a self-weighted sample using two-stage cluster sampling. In addition to the lack of wide social network, the inadequate resources for comprehensive social mapping create challenges to enrolling hidden and marginalized population in IBBS survey. Good quality of secondary information (demographic information) is a prerequisite for developinga sampling frame during the initial mapping intwo stage sampling. Field management staff needs to be aware of these challenges during initial mapping and real mapping in order to detect large variation in size of clusters. Selecting clusters based on probability proportions of size should be avoided if there is a wide estimated variation in cluster size between the initial and second real mapping exercise. It is then better to select a cluster with equal probability and adjust for the non self-weighted sample in the analysis[18].

We found that the most likely error to occur during field work is a biased sampling frame derived during the real mapping of two stage cluster sampling. The sampling frame is largely based on the information provided by the NGOs or on individuals who are seeking services such as HIV prevention, treatment, care and support services from NGOs. However, in practice, IBBS survey field staffs make inadequate attempts to list possible survey populations within the sampling frame who are not taking part in any HIV prevention services provided by NGOs. Therefore, parts of the survey population remain hidden and are not reached by this sampling procedure. The problem is further compounded by the criminalization of sex work and illicit drug use in many countries including Nepal. This makes it even more difficult to list possible hidden members of the target population in the sampling frame. The challenges in sampling hidden populations undermine the generalizability of the survey findings to the whole target population, *e.g.* sex workers or PWID.

In the 2012 IBBS surveys in Nepal, a new successful strategy was used to map hidden PWID in a sampling frame. Those PWID who recently had received services from certain NGOs were approached by the survey field staff and informed about the IBBS survey objectives and confidentiality of participation. PWID were also asked to provide information about friends who inject drugs and meeting places of PWID not in touch with any NGOs. They were also asked to inform drug-injecting friends about the IBBS surveys. Thereafter, survey field staff approached the hidden PWID or locations in a confidential manner to enlist them in the sampling frame. The information about informant PWID was not shared with any other hidden PWID and confidentiality was kept at every stage. This approach was found to successfully reach and recruit those PWID who were not attracted by the survey incentives to participate in the IBBS survey.

Another common validity problem is the overestimation of personal network size especially among MSM and the failure to adjust for violations of RDS assumptions during data analysis. Poor structuring of network-size related questions including unclear definitions of the survey area contribute to overestimation since respondents can also report other MSM living outside of survey area to be part of their personal network size. Asking survey respondents about a network size in a longer time frame, it was 12 months the case of Nepal-might also result in reporting recall bias. A possible solution for this issue is modifying or restructuring the questions related to personal network size. Internal validation within the survey by asking about the network size in several ways has been used to improve accuracy of the reported network size by respondents[26]. This includes specific questions regarding the participants' social network, the nature of their friendship (close friend, friend, lover, sexual partner, relative), specifying a certain time frame for their friendship (at least two different time frames), frequency of interactions within their friendship (how often to do you talk?) intimacy of their friendship (Is this someone you are comfortable talking about personal issues with?).

Another possible solution to address the issue of overestimated network size in RDS is to explain these questions thoroughly and by giving examples and tips of how to estimate a respondents network size, for example by checking cell phone contacts, and thinking of number of people they have met during the last week. It is also important that enough time is allocated to the survey to allow the participant to think thoroughly about the questions that relate to estimates of social network size. During the planning phase and data collection, we recommend conducting meetings between NGO leaders and front-line care providers

(peer educators, social mobilizers) to get their input and feedback to improve the study and recruitment, and to provide updates regarding the survey. The importance of personal network size and how it affects the study findings and estimates should be clearly explained to all stakeholders. It may be helpful to involve the NGO leaders and front line care providers in the development of appropriate personal network size question. A formative assessment also needs to be performed by interviewing key stakeholders within the MSM community to find a possible explanation for this. Consistent under-or-over reporting of personal network size or degree cannot influence the estimator of RDS because estimator equations are based on relative degree reports[17]. But no systematic evaluation has been done in Nepal to identify whether the error reported in self-reported network sizes by MSM are systematic or random (differential or non-differential reporting of network size).

In the analysis of RDS-related data, it is important to evaluate if the RDS assumptions have been fulfilled, and we recommend reporting both crude and RDS-adjusted estimates in the results of the survey. This is the most transparent way of reporting data and the impact of the RDS-adjustments. The presentation and analysis of RDS related data as per the guidelines of the 'strengthening the reporting of observational studies in epidemiology for RDS studies[38] also helps to ensure the sensitivity and representativeness of survey findings.

4.2. Supporting public health action

A long questionnaire has been in use for the IBBS survey in Nepal, which may bore the respondents and provoke them to either discard or not answer all of the questions[39]. This has resulted in many missing values and sometimes a low response rate. Some studies found that *e.g.* substance use was more common among less enthusiastic or interested respondents leading to systematic bias in relation to other respondednts and affecting the reliability of the results[40]. The IBBS survey questionnaire used should be continuously updated in consultation with the people who are involved in HIV prevention program implementation to come up with a feasible maximum length and variables that provide little or no information for evaluation or planning of public health interventions should be removed.

After two rounds of IBBS surveys (2003/2005) among PWID in the Terai Highway Districts, the survey team realized that one of the major assumptions (one network component or member of the survey population are networked) of RDS was violated and then recommend to switch to two-stage cluster sampling. Network bottlenecks between the respondents prevent accurate sampling and may lead to inaccurate estimates, but were rarely adjusted for during data analysis. This problem could have solved by conducting formative assessment, before implementing IBBS survey, to identify the demographic features of the vulnerable populations and the applicability of RDS[41,42]. Nepal, as many other settings where HIV transmission is high, is also experiencing rapid demographic changes and population movements such as migrant laborers going to overseas to other East Asian countries or to the Middle East but very limited evidence is available to account for these changes in the sampling populations[43]. Recently, a project started HIV related behavioral surveillance survey in districts outside of three HIV epidemic zones targeting among returnee migrant worker from overseas other than India[44].

4.3. Ensuring a prompt response to the HIV epidemic

All the personnel directly or indirectly involved in survey field management process from the beginning helps to facilitate communication between different institutions and individuals during the field work. If collection of IBBS data is delayed timely reporting of intervention impact to concerned authorities, donors and stakeholders will also be delayed in turn limiting timely utilization of data with implications for evidence-based planning and future surveillance activities. In Nepal, IBBS survey data is the primary source for HIV infection projections and the basis for program target setting such as numbers needing antiretroviral therapy and pregnant women requiring prevention of mother-to-child transmission services. Each IBBS survey site is considered as a sentinel site for HIV prevalence data and behavioural data over time. Robust and precise estimate of HIV dynamics is therefore essential for accurate programme targets. We thus recommend providing comprehensive training on IBBS survey implementation including all concerned personnel working with the IBBS surveys-from programme management, administration and finance, to logistics supply chain management, strategic information and planning.

4.4. Study limitations

The fact that the researchers (co-authors) were also team members formally hired to monitor field work who might have influenced the response from the key informants[24]. The emphasis on identifying mistakes or problems may also give skewed picture and positive efforts may therefore not be properly highlighted resulting in less constructive feedback. This may affect the observation process and hinder honest responses from the key informants even during casual conversations about the challenges they are facing to ensure survey standards in field.

4.5. Recommendations for overall IBBS survey management in Nepal

4.5.1. Preparation before the survey field work

NCASC and its partner organizations should ensure that selected research organizations: who are responsible for conducting IBBS survey field work) are coordinating about

the survey process to community people (for example NGOs running by the target population and working for the sexual and reproductive health rights of survey populations). The most important thing is to ensure whether research organizations are aware of the main objective of the IBBS surveys (*i.e.* describing trends over a period of time, not the estimate of one point in time), because it has huge implications in report writing and dissemination of survey findings.

NCASC in consultation with technical partners and IBBS experienced research organizations, including the key population networks need to update and modify survey questionnaires and techniques/process.

IBBS survey team leader (often known as principal investigator of the survey) or technical consultant should closely observe the sampling frame developed during initial mapping (in case of two stage cluster sampling). Also review whether the cluster defined in two stage sampling is up to standard (*i.e.*, clear physical demarcation between clusters). Example: If a bus park area is divided into A, B and C clusters, the field staff should able to know where area A starts and ends, and where areas B and C begin.

Survey team leader or technical consultant should assist research organizations in development of training schedule (designed for field staff) and properly ensure that the proposed training schedule is robust enough to make aware field staff about the sampling techniques and its assumptions, survey populations, ethical and lab issues and security of completed questionnaires. Do not forget to share the draft questionnaire with field staff and request them to provide any comments on questionnaire. Team leader or any other responsible technical staff should check the entire final questionnaire, including informed consent and other extra sheet, before sending it to press for printing.

Research organizations need to provide a detail field plan (data collection period, survey filed team names and contact details, clinic set-up sites) to survey team leader or technical consultant. NCASC needs to develop a joint field monitoring team, and develop standard checklist before field work and share with key technical partners if they can join the field monitoring of IBBS survey.

Survey team leader or technical consultant should ensure that research organizations have adequate laboratory tools, testing kits, drugs, reagents, and recording and reporting forms. Also request research organizations to send bio-data of person who are responsible for data management and guide them in development of database, including code book (describes the name, meaning, and coding of each variable) and its management in different databse management software. Also assess the technical competencies of person who are involved in survey data management and recommend for training (if required).

Training on survey objectives, survey populations and settings, major methods, field monitoring process for quality survey results to all survey team is critical for success.

4.5.2. Implementing the survey

Survey team leader or technical consultant should regularly update to NCASC-surveillance and research team about the clinic set-up sites and request NCASC to execute joint monitoring plan. The monitoring team should consist of different experts (epidemiologists, behavioral scientists, laboratory experts, programme management officers, *etc.*). The monitoring team should clearly observe the development of sampling frame and recruitment of possible survey participants because these two things have huge implications for estimates of prevalence and other key variables. Those who are involved in monitoring should also be aware about the methodological assumptions of the survey techniques selected.

After the field visit, members of joint monitoring team should share the field situation (written, verbally, as soon as possible) at the centre (with responsible institution), with other key stakeholders and research organizations. Joint field monitoring team should avoid being overly critical and making mean comments, especially to the field staff.

Technical consultant should ensure that biological samples and other survey materials are properly transported to the centre. Research organizations should finalize database and codebook. Consultant and other responsible authority should regularly contact field staff from the centre and update about the field status to the centre and with other stakeholders.

Any deviations from pre-planned activities or new strategies used to develop sampling frame or process to recruit hidden possible survey populations need to be documented properly for the future reference.

4.5.3. Analysis and advocacy of survey information

Survey team leader (responsible staff of NCASC) or technical consultant should double-check the appropriateness of databases (question responses, skip pattern, *etc.*) developed by research organizations, and also run few randomly selected variables.

Consultant should request research organizations to provide their team members with a list of who is responsible for data analysis, report writing and development of contents for local and national level dissemination. If a consultant suspects that research organizations did not have adequate members in a team for data entry, analysis and writing, he or she should contact central quality control officials and conduct immediate meetings with research organizations to sensitize them about the importance of on-time quality deliverables.

Survey team leader of NCASC should be responsible for organizing meetings with the programme people who are responsible for implementing HIV prevention, treatment, care and support services before writing the full report. Technical consultant should document and share recommendations with research organizations made by the programme people for this purpose (including data interpretation). If possible, conduct small meeting before sharing key findings with the programme people of different international and national

NGOs working in HIV field and request them to identify the selection of key variables for the analysis.

Technical consultant should guide research organizations in data interpretation and development of necessary materials (power points, factsheets) for disseminating survey findings at community, regional and national level. Survey team leader or consultant should review and provide comments on draft IBBS reports, factsheets, and power points developed by research organizations for different level of disseminations.

We have summarized recommendations for more effective management of IBBS surveys in Nepal and hope that these recommendations can be applied also in other low income settings implementing IBBS surveys.

Conflict of interest statement

We declare that we have no conflict of interest.

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