

DRAFT

Applying HIV/AIDS Survey Methodology across Cultures

A. Introduction

Survey research on HIV/AIDS in the United States (US) has an established record of successes and disappointments with different approaches. These models or approaches could offer important lessons for countries newly confronting the need for this research in their own backyards.

HIV/AIDS surveys have been conducted for a variety of purposes and on a diverse set of populations. Early studies in the US centered on collecting information to evaluate HIV/AIDS prevention programs, track the spread of the HIV¹, and understand the behaviors associated with risk of acquiring the infection. These surveys were carried out on the general population and on members of specific target groups of interest, including intravenous drug users, commercial sex workers, and men who have sex with men (MSM). Study design frameworks used in the US include qualitative and quantitative techniques such as in-depth surveys, focus groups, local observation methods, and randomized experiments.

As more countries and cultures struggle with rising HIV infection rates and diminishing resources to cope, expedient and effective “tried-and-true” methods to study and measure the factors impacting HIV/AIDS issues are sought. Here we discuss some points to consider in the process of choosing and implementing these methods in the “new” country context.

B. Important Considerations for Cross-Cultural Research on HIV/AIDS

A challenge faced by HIV/AIDS survey researchers is the transference of survey methods that function in one cultural context to other contexts that might have conflicting cultures or core values. Sometimes when carrying out research in other cultural contexts, the “reflex” is to impose the structure of an approach that has worked in the US onto that new context. This is commonly done without regard to perceived or actual differences in the cultures. The differences, real or otherwise, might include cultural taboos, legislation, level of experience with survey research methods, norms of self-presentation, and privacy protections, to name a few.

Here we show a simple framework for a commonly used approach to doing survey research. The four-stage approach is applied to other countries and contexts in a generic fashion; i.e., regardless of the unique characteristics of the cultural setting.

¹ While surveillance activities to track HIV/AIDS transmission have been important study tools, this paper focuses on surveys and associated methodological research.

General HIV/AIDS Survey Approach Framework: Four Stages

Stage 1	Research Objective
Stage 2	HIV/AIDS Study Population
Stage 3	Methodological Approach
Stage 4	Study Results

Stage 1: The research objective is clearly stated.

Stage 2: The target HIV/AIDS study population is defined to meet the objectives of the research.

Stage 3: The survey methodological approach to be applied is selected based on what is commonly or traditionally indicated. The approach is implemented.

Stage 4: The study results are obtained, but the influence of cultural factors on the quality of the data collected is unknown. Conclusions are drawn that could be erroneous if important cultural factors have been under-examined or ignored.

An expanded framework is preferred that gives attention to the cultural context and permits modification and pretesting of the methods being applied, based on what has been learned from the assessment of the country or culture of study.

Cross-Cultural Survey Approach Framework: Six Stages

Stage 1	Research Objective
Stage 2	HIV/AIDS Study Population
Stage 3	Methodological Approach
Stage 4	<i>Cultural Context</i>
Stage 5	<i>Modified Methodological Approach</i>
Stage 6	Study Results

Stages 1, 2, and 3: Same as above.

Stage 4: The cultural context of the study is noted. This stage is critical stage, where perceived or actual cultural differences may be acknowledged but often are ignored. Here cultural differences are noted, explored, and understood, but not ignored. A need for modifications to the proposed approach is recognized. The approach is implemented and pretesting takes place.

Stage 5: The approach is modified based on an assessment of the country context. Potential gains and losses are realized. Steps are then taken to compensate for possible shortcomings of the modified approach.

Stage 6: The study results are obtained and reported with a fuller knowledge of the cultural effects. Cultural biases are minimized.

C. A Short History of Approaches/Frameworks Used in the US

When used individually or in combination, survey techniques can serve as effective tools for the measurement of HIV/AIDS risk behaviors. The National Research Council Committee on AIDS Research published in 1991 a short synopsis of methodological issues encountered in the process of collecting survey data on HIV and AIDS (Coyle, Boruch and Turner, 1991). This useful summary provided important information on the possible error and bias in existing approaches, but offered evidence that surveys could

provide helpful and replicable results, and that the cooperation of the target populations was possible and feasible.

Since that time, HIV/AIDS research activity in the US has been productive and expansive, to the point where it can offer examples for other countries just forming their agendas to study this problem. It is important to note that over the past 25 years of research in the US, norms of self-reporting might have changed, so that inferences derived from early studies are not necessarily true for the present, or cannot be assumed to be true in other country settings.

Surveys concerned with HIV/AIDS in the US have faced a combination of circumstances and problems that, over the past two decades or so, have shaped the survey research models in use. The target high-risk populations that are frequently of interest are often rare and the risk behaviors are socially stigmatized, creating both sampling and data collection difficulties. The design of surveys is often further hampered by the fact that the information needed for design and implementation is not infrequently limited or unreliable. For example, data on the prevalence and location of populations such as MSM or intravenous drug users may not be of sufficient quality for effective sampling.

In many instances, the combination of poor data for planning and limited resources have led to the use of compromise methods that bring with them serious limitations for the resulting research. For instance, much of the early work on MSM relied on convenience samples that could not support generalization to the larger population of interest.

Focus groups became popular in the mid-1990s to study drug abuse and HIV/AIDS; early works applying this technique did not mention the special methodological and pragmatic issues concerned with the design, implementation and analysis of focus groups with these research populations (Shedlin and Schreiber, 1995).

In recent years there have been some moves away from these approaches. In some cases, full general population probability samples with built-in screening have been designed and implemented. Catania et al. (200X) report on a random-digit-dialing (RDD) survey that screened for MSM in four major cities. In others, probability samples of more narrowly-defined populations, for example, customers of select venues such as gay bars or bathhouses, have been conducted and analyzed with proper recognition of their limitations (Binson and Woods, 200X) *bathhouse book*). The literature has begun to include more guidance on alternative methodologies, their uses and limitations (Binson, et al. 20xx *sampling chapter*).

D. Survey Research Models

Survey research methodologies and models used in the study of HIV/AIDS include elements and components that can be affected by the particular data needs of the country or cultural group.

Selected methodological components potentially impacted by cultural issues

- Sampling
- Recruiting
- Screening
- Instrument Design
- Data Collection Mode

Sampling, Recruiting and Screening

Many early studies of MSM or intravenous drug user populations have been based on convenience samples of locations where population members reasonably can be expected to be found. This type of design has well-known shortcomings. Some of these result from choosing survey respondents with unknown chances of selection, while at the same time not giving other members of the same population a chance for inclusion.

The use of venue surveys that employ probability samples has become an alternative that provides for some ability to generalize and the possibility of replication of results. An example of a venue probability sample might involve selecting a venue; e.g., a gay bar or bathhouse, and then using either a time-location sampling procedure (for the former) or a membership list (for the latter) to select a sample with known probabilities of selection. Such a survey, carefully implemented, permits generalization to at least those limited populations of patrons. If, for either venue, several establishments in a city were randomly selected and then within each establishment patrons were selected, then the sample could be used to properly estimate characteristics of those populations of patrons for the city.

In attempting to locate a target group, say MSM, within the larger general population, a simple screening survey could be conducted. In that instance, the sample would be selected using standard RDD or area probability sample designs and then screened to locate the target group. In principle, this approach is sound; in practice, it can be quite costly to conduct. The prevalence of the target population is known only approximately, usually from data that either are not for the specific geographic area in the survey or that was obtained from a non-screening method, such as a general survey that included questions about population membership. In either case, there is a high risk that the actual screening prevalence will be lower than expected, with serious cost implications. Such studies have been most successful when confined to limited locations, such as well-known gay neighborhoods, known to have a high proportion of the population of interest.

More complex sample designs have been used to address some of these difficulties. For example, two-phase designs in which the first phase screens enough households in a stratified sample to confirm or adjust the prevalence estimates for each stratum; while the second phase sample in each stratum can be adjusted to match the updated prevalence estimates (Blair, 1999). These types of adaptive designs, in which the sampling procedures in one phase are adjusted based on data from an earlier phase, are promising approaches, but require special sampling expertise to properly implement. Similarly, approaches such as network sampling or respondent-driven sampling that depend on a set of modeling assumptions and complex selection and estimation methods are feasible, depending on the extent to which the assumptions hold and the selection are practical to implement within resources.

Finally, there are many instances of the use of special population lists, particularly for program evaluation, when the program participants are identifiable in an available frame. Surveys of program participants in clinical studies, for example, make use of this approach. The sampling issues are much more straightforward than in general population screening surveys.

Instrument Design, Mode and Data Collection

The related data collection issues are key to successful survey implementation: self-report accuracy and mode of survey administration. Choice of mode, whether it be in-person interviews, focus groups, participant observation, or RDD, has the largest effect on survey cost, but it can also have an impact on the accuracy of reporting sensitive or socially-proscribed behaviors.

Equally important is the strength of social taboos and stigmatization. While many MSM or target groups will not self-report their status in a survey, substantial numbers will. Part of the decision to report is influenced by perceived risk of disclosure. The survey sponsorship, purpose and assurances of confidentiality all play a role in respondent perception of risk.

Panel or longitudinal studies have been attempted in particular to study changes over time in respondent attitudes toward HIV/AIDS and in their participation in the survey process. The key to this mode is how much attrition occurs from wave to wave of the panel, and how much bias in the results is thereby introduced. A CDC study of stigma associated with HIV/AIDS found the need for better methods to improve the participation of groups that were reluctant to participate at all, or who had dropped out between waves (Baxter and Dean, 2004).

E. Applying US Approaches to Developing Countries

How well do research techniques that have been applied in the US transfer to other countries and cultures? Techniques that have proven effective on population groups in the US do not necessarily have the same results when applied to foreign populations. This can occur for several reasons that might or might not be intuitive.

Research organizations involved with surveys of HIV/AIDS internationally have employed, with some degree of success, a diversity of methods in their projects,² although these approaches have not been without their limitations. Because of the special features of non-US contexts, it cannot always be ascertained ahead of time what approaches will prove effective and what will not. Careful attention must be paid to the process used to develop, test and implement a particular survey technique or set of techniques. The literature on cross-cultural surveys and the technical reports of the methodology used in these surveys suggest that many of these surveys do not take full advantage of available instrument development and testing techniques, pretesting in particular (Blair and Piccinino, 2005).

² The POLICY Project/USAID; MEASURE/UNC-Chapel Hill; IMPACT/Family Health International; and AIDSQuest/Population Council are some examples.

Many issues that are apparent in other countries are the same as or similar to those found in the US, although some issues might be more intensified or more sensitive in the non-US setting. This indicates that there is an additional range of cultural and communicative issues that should be addressed when designing surveys within non-US contexts. These types of issues, including norms and behaviors, often are unintentionally overlooked when surveys are designed for another culture or meant to serve as a standard core that can be adapted to multiple cultures.

The US population has been well-studied, surveyed and canvassed, and is accustomed to being asked to participate in the survey process. People in other countries might not have had the same exposure, or might not be receptive to the idea of being surveyed, as their history or traditions might dictate. It is important to recognize that in conducting surveys in these types of cultural environments, extra steps might need to be taken to explain the purpose of the survey process to the target population in order to achieve more accurate responses and results.

Presented below are some issues that can have an affect on the type of survey approach being applied.

Cultural issues affecting survey approaches

- Research context
- In-country experience with survey research methods
- Privacy/confidentiality assurances
- Stigma/Taboos
- Sensitivity of survey topic

The context of the research plays a major role in the selection of an approach and is dependent on the participation of local NGOs and stakeholders³. This can be problematic, because cooperation is sometimes episodic, especially where partnerships are politically-charged. Another possible limitation of the research context is that NGOs and other stakeholders are given equal weight in the sample design. For example, an approach that called for fielding a qualitative assessment guide with stakeholders, as was done in Vietnam to understand leadership potential and level of national political commitment to the HIV/AIDS problem, had its own biases (Duong, 2005). Respondents were assumed to be equally knowledgeable about the issues, when in fact that was not necessarily the case.

Social and political attitudes might also foster an environment where potential survey supporters might perceive HIV/AIDS as something that has nothing to do with them, as

³ For example: Government, mass media, donor organizations, NGOs, faith-based groups, academia, and so on.

was the case in parts of Eastern Europe (Goodwin et al., 2003). Survey success is better assured when there is ‘buy-in’ from stakeholders. The research context should be one where the local vendor and other in-country experts appreciate the value of and provide resources for pretesting of instruments and procedures.

The level of experience with survey research methods that in-country personnel have can help or hinder the survey process. Too little experience indicates that there are more training requirements. Those with more advanced experience need little basic training, but might require retraining to “undo” training practices learned from other donor organizations, especially in countries where donor activity is high and qualified staff are scarce. For qualitative survey research in developing countries that are conducting surveys for evaluation purposes, one group of researchers advises the use of local social scientists that are skilled in qualitative methods to help with the data collection (Hogle and Sweat, 2005). While this might be the preferred case, experienced help is not always available. In this situation, local expertise might need to be substituted with more intense training efforts and more involvement of donors, stakeholders and other experts.

Methods to address privacy concerns and assurances of confidentiality can include, for example, advance letters to directors of organizations, health ministers and other stakeholders to help establish the legitimacy and official nature of the survey research being conducted. In societies that are fearful of government intervention, as another example, extra precautions could be taken to remove the “trappings” of government such as official seals and logos on paper questionnaires and other materials that might be seen by the respondent. Other precautions include additional testing or removal of “sensitive” items; this should be performed in advance of fielding the instruments.

Perhaps one of the most salient reasons for potential problems with non-US-based populations is the high level of stigma attached to the disease and to the population that it afflicts. The issue of social stigma has been prominent in HIV/AIDS research. It has been an issue that has required special attention in the design of survey techniques that it might impact, and can be a barrier at many levels. Efforts to reduce stigmatization in the US have been partially successful (Jarlais et al., 2006), but stigma continues to be a greater problem in other regions of the world; e.g., in Asia and Eastern Europe⁴.

Earlier we discussed some of the approaches used in HIV/AIDS surveys in the US and some of the methodological issues. We now explore how certain methodological components might have an impact on cultural issues.

Sampling – For many countries the use of a randomized survey is not a feasible option. This is usually due to several factors, including issues of equity, ethics and limited resources. For example, when the survey is being used to evaluate an intervention where the treatment areas have been “hand-picked” based on political and geographic preferences, or where staff and funds for probability sampling are scarce, other sampling options must be considered. Sampling frames in many countries often can prove difficult

⁴Stigma has become an issue of study in itself, and “remains one of the most poorly understood aspects” of the HIV/AIDS pandemic (Parker and Aggleton, 2002).

to administer, are incomplete or out-of-date, or are politically unpopular. Data specific to special subpopulations (e.g., intravenous drug users, MSM) frequently are not available from national or international sources; if these do exist, the data might be difficult to locate and access.

Recruiting and Screening Tools – Depending on the context, the screening and recruiting activities can be conducted in an open manner or must be kept clandestine. Nevertheless, it is acknowledged that some sensitive or invasive questions need to be asked at the beginning of the interview process. Asking MSM about their sexual preference or HIV status, for example, is much different in the context of a health or sexual behavior survey than in a short screener instrument.

The level of cooperation or response in cross-cultural surveys can be limited by fear of reprisals or the lack or loss of confidentiality and privacy assurances. Some countries, by nature of the level of HIV/AIDS risk behavior or rising infection rates, suffer from the problem of being over-studied or over-sampled; the target population becomes fatigued or reluctant to participate in surveys. On the other hand, response can be overwhelmingly positive, a habit of compliance leftover from past regimes, as in some former dictatorships where cooperation was required. Incentives might be used where survey participation rates are low, but investigations into the type of incentive that is appropriate for the level of effort and the target population must first be carried out.

Instruments and data collection mode are dependent on the appropriateness of the language being used, the dialect, and the level of literacy of the target population. These could indicate a possible need for several versions of an instrument. Qualitative techniques such as participant observation – which involves unstructured interviews and unstructured observation – relies on researchers that are part of the culture, know the language, and who are connected with a group that can help contribute to a more accurate description (Hogle and Sweat, 2005). This technique was attempted recently in studies in Eastern Europe to study MSM risk environments. Although the studies provided useful information, it was later found that their utility was limited because the focus groups did not provide enough insight into how MSM construct their identities (e.g., as gay, bisexual or heterosexual) or how their identities influence their behavior.

Some of our recent experiences with survey methodology projects are presented here to help illustrate how a set of US methodologies is transposed onto issues for non-US contexts.

Selected Examples of Non-US HIV/AIDS Survey Approaches

US methodology/ approach	Non-US research context	Modifications to US methodology/ approach	Cautionary notes
1. In-depth surveys by local interviewers	Central Africa	Re-training; in-country professional staff reallocated; increased involvement of local stakeholders	Local resources were cut unexpectedly
2. Establishment surveys/Global Web-based Survey and Stakeholder Analysis	West Africa	Standardized to fit generic context; adaptations made for individual countries	Surveys designed for West African context only; need to extend to Asia & other countries
3. Snowball sampling; qualitative interviews (focus groups, participant observation)	Eastern Europe/Central Asia	Creative sampling/recruiting solutions; sample areas redefined	Highly-stigmatized “underground” population; NGO collaboration mixed

The first example is from a study in Central Africa tasked to develop data collection instruments by either adding to existing surveys/records, or by creating new HIV/AIDS specific surveys. Here researchers tried in advance to understand the advantages and limitations of various methodological approaches to developing these instruments, and planned their data collection activities accordingly. Unfortunately, the level of in-country survey experience was such that only a few researchers were available with the skills necessary to implement the chosen approach. When skilled interview staff proved inadequate and data collection tasks were not properly monitored because of competing project demands on the researchers’ time, a modification of procedures and mid-project retraining proved critical to the success of the approach.

In the second example, the set of establishment surveys was initially designed for use in West Africa. An added complication was that the survey was to be implemented in several West African countries was also proposed for use in a single country. Further, these surveys were intended to be conducted on several countries in Africa and Asia, and needed to be designed so that a single survey could be made adaptable to multiple cultures.

In the third example, snowball sampling was the method chosen to sample and recruit participants for the focus groups and in-depth interviews. This proved to be effective for members of the MSM community that were very “open,” but did not provide a satisfactory alternative for reaching other latent members of the MSM community. More investigation (through the use of key informants) into the culture of communication

within MSM networks was needed before a more appropriate set of sampling methods was decided upon for the data collection.

Because of the experience of previous studies of MSM in Eastern Europe, and because social taboos and stigmas only allowed for a discussion of MSM behavior in general (not individual-specific), it was decided that personal information about sexual identity be asked using a self-administered questionnaire at the conclusion of the focus group interviews. This method helped assure the privacy of the participants. At the same time, it capitalized on the rapport built during the focus group session. This helped participants to gain more confidence in the legitimacy of the research process and in the assurance of confidentiality so that respondents were more open to disclosing personal information on the self-administered form.

F. Summary

We have examined models of HIV/AIDS research applied in the US, and the utility of these approaches for work in other cultures. Some specific approaches used in real-life settings were presented to illustrate various survey research methods used to measure and evaluate the values and behaviors surrounding the AIDS pandemic. The importance of using sound survey research methodologies so that false conclusions are not reached is underscored.

We know that challenges continue to burden the conduct of HIV/AIDS studies in different countries or in countries with a variety of different cultures. We hope to help to demonstrate that there is a need to examine further what has and has not worked in the US context, which lessons in particular can be applied successfully to other settings, and why some cannot.

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