

## **HIV behavioural surveillance surveys in conflict and post-conflict situations: A call for improvement**

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### **Abstract**

Behavioural surveillance surveys (BSSs), an evolution from the knowledge–attitudes–practice surveys (KAPs), are a tool to track trends in HIV/AIDS knowledge, attitudes and risk behaviour among populations. The data collected support organizations in targeting specific HIV/AIDS prevention and care activities, monitoring their effectiveness and coverage, and allocating scarce resources. The objectives are to evaluate the quality and standardization of BSS-like surveys undertaken in conflict and post-conflict situations, and to provide recommendations to humanitarian agencies and governments on how to improve their quality. Survey methodology was classified as reproducible if the population-based sampling defined a sampling frame using probabilistic sampling. Survey indicators were compared to internationally-accepted HIV indicators. The results showed that 14 (45.2%) of the 31 BSS-like surveys evaluated between 1998 and 2005 in 14 countries were classified as reproducible. Surveys undertaken by non-governmental organizations (NGOs) were significantly less reproducible than those undertaken by non-NGOs ( $p = 0.05$ ). The majority of surveys used at least one identical or similarly worded internationally-accepted HIV indicator for prevention and misperception but not for practice and attitudes. Few reported disaggregated indicators according to age or gender. It was concluded that the majority of BSS-like surveys are of insufficient methodological rigor to be reproducible. Few surveys reported internationally-accepted HIV indicators by gender and age which makes interpretability and comparison difficult. United Nations agencies, NGOs, and governments undertaking BSSs in conflict and post-conflict settings should proceed with a BSS survey once the design and plan for execution has been prepared by experienced and qualified experts. These experts should then oversee the survey, assure data quality and incorporate training of others in the process. A practical and field user-friendly BSS manual is needed for conflict affected and displaced population situations, one which is customized to take into account the special circumstances of such populations.

**Keywords:** *HIV, AIDS, behavioural surveillance survey, humanitarian emergency, conflict, post-conflict, refugee, IDP, methodology and quality*

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## **Introduction**

The human immunodeficiency virus (HIV) behavioural surveillance surveys (BSSs), an evolution from the knowledge-attitudes-practice surveys (KAPs), are an assessment, monitoring and evaluation tool designed to track trends in HIV/AIDS knowledge, attitudes and risk behaviour among populations. When used together with qualitative and quantitative research and proper measurement of appropriate programme indicators, the data collected from BSSs can assist organizations in targeting specific HIV/AIDS prevention and care activities, allocating scarce resources, and monitoring and evaluating the interventions' effectiveness and coverage. BSSs are useful because they alert policy makers and programme managers to emerging or changing risks in existing behaviour, reveal gaps in knowledge and attitudes, help to identify vulnerable segments of populations, contribute to improved programme content, provide data on specific target groups and ensure compatibility and standardization of data collection (Family Health International 2000).

The core BSS indicators have been evolving over time (Table I). Until the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) indicators were developed in 2002, there were no internationally-accepted HIV indicators. The UNGASS indicators were followed by the development of the Millennium Development Goal (MDG) indicators in 2003 and, subsequently, the US President's Emergency Preparedness Fund on AIDS Relief (PEPFAR) indicators in 2004. Although all of these indicators are similar to one another, there are minor differences. Thus, it is difficult for persons implementing BSSs to choose which indicators to use and complicated for others to compare studies which use different indicators. Furthermore, there are numerous other indicators that can be used in BSSs depending upon the target groups and objectives of the survey.

Conflict, displacement, food insecurity and poverty have the potential to make affected populations more vulnerable to HIV transmission. The UNGASS Declaration of Commitment on HIV/AIDS, states that 'populations destabilised by armed conflict ... including refugees, internally displaced persons, and in particular women and children, are at increased risk of exposure to HIV infection' (United Nations General Assembly 2001). However, the common assumption that this vulnerability necessarily translates into increased HIV infections and consequently fuels the epidemic is not supported by data (Spiegel 2004). In the recent past, HIV/AIDS interventions were generally not included by humanitarian organizations as part of their immediate response to conflict; HIV/AIDS was considered more of a developmental issue and not an immediate life threatening disease such as malaria or cholera. However, thinking has evolved and it is now generally accepted that HIV/AIDS programmes must begin at the onset of a humanitarian emergency, be multisectoral, and continue at every stage thereafter (Inter-Agency Standing Committee 2003). Furthermore, for refugees and internally displaced persons (IDPs), HIV/AIDS programmes should be integrated

Table I. Internationally accepted key BSS indicators.

Knowledge	International standard
<b>Prevention</b>	Percentage of young women and men aged 15–24 years who, in response to prompted questions, say that: 1) <i>people can protect themselves from contracting HIV by having sex with only one faithful, uninfected partner.<sup>a</sup></i> <b>UNGASS, MDG, PEPFAR</b> 2) <i>people can protect themselves from contracting HIV by using condoms.<sup>a</sup></i> <b>UNGASS, MDG, PEPFAR</b>
<b>Misconceptions</b>	Percentage of young women and men aged 15–24 years who, in response to prompted questions, correctly reject that: 1) <i>A person can get HIV from mosquito bites.<sup>a</sup></i> <b>UNGASS, MDG, PEPFAR</b> 2) <i>A person can get HIV from sharing a meal with someone who is infected.<sup>a</sup></i> <b>UNGASS, MDG, PEPFAR</b>
<b>General</b>	Percentage of young women and men aged 15–24 who, in response to prompted questions, know that: 1) <i>A healthy-looking person can have HIV.<sup>ab</sup></i> <b>UNGASS, MDG, PEPFAR</b>
Attitudes	
<b>Care and support</b>	The number of respondents who report an accepting or supportive attitude of: 1) <i>Would be willing to care for a family member who became sick with the AIDS virus.</i> <b>PEPFAR</b> 2) <i>Would buy fresh vegetables from a vendor whom they knew was HIV+.</i> <b>PEPFAR</b> 3) <i>Female teacher who is HIV+ but not sick should be allowed to continue teaching in school.</i> <b>PEPFAR</b> 4) <i>Would not want to keep the HIV+ status of a family member a secret.</i> <b>PEPFAR</b>
Practices	
<b>Condom use</b>	1) <i>Percent of men and women (aged 15–24) who used a condom at last sex with a non-marital, non-cohabiting partner, of those who have had sex with a non-marital, non-cohabiting partner in the last 12 months.<sup>bc</sup></i> <b>UNGASS, MDG, PEPFAR</b>

<sup>a</sup> prior to the UNGASS indicators in 2002, the UNAIDS stated indicators did not specify youth (15–24 years).

<sup>b</sup> the MDG indicator replaces ‘have’ with ‘transmit’.

<sup>c</sup> the MDG indicators do not specify ‘non-marital, non-cohabiting’ but add ‘high risk’. PEPFAR uses 15–49 years.

with the surrounding host population response and a sub-regional approach undertaken in order to take into account the displacement cycle (UNHCR 2005).

Timely and accurate data are needed to provide targeted and effective interventions in conflict and post-conflict settings. Unfortunately, due to unstable

situations and lack of epidemiological expertise in many humanitarian agencies, the data provided are often unreliable (Boss et al. 1994, Spiegel et al. 2004). To assess the quality and standardization of BSSs, and its predecessor, the KAP survey, undertaken in conflict and post-conflict situations, we evaluated the methodological quality and use of internationally-accepted indicators of these surveys conducted among refugee, IDP, host community, returnee, conflict and post-conflict populations. Recommendations were then provided to humanitarian agencies and governments on how to improve the quality and standardization of BSSs among conflict and post-conflict populations.

## **Methods**

We collected all available HIV BSSs and reproductive health KAP surveys with an HIV component in refugee, IDP, host population, returnee, conflict and post-conflict settings. This was accomplished by undertaking a literature review using PubMed, by searching the internet for key words (i.e. HIV, behavioural surveillance survey, BSS, knowledge, attitudes practice, KAP, refugee, internally displaced person, IDP, returnee, conflict and post-conflict), and by contacting UN offices in affected countries and non-governmental organizations (NGOs) which undertake such surveys (e.g. Reproductive Health Response in Conflict Consortium, International Rescue Committee) and organizations which specialize in undertaking such surveys (e.g. Family Health International [FHI], US Centers for Disease Control and Prevention [CDC]). When titles or abstracts of surveys were found, but the actual report was not available, authors and organizations responsible for the report were contacted directly. Inclusion criteria were any BSS or KAP survey with a quantitative HIV component undertaken among affected populations, listed above, where a written report was available. Exclusion criteria were surveys with an HIV component in the affected populations that were solely qualitative, and nationwide surveys that may have included one or more of the affected populations but where results were not disaggregated to differentiate them from the overall population, and where reports were unavailable.

The survey reports were collected, evaluated, categorized and entered into an EpiInfo 3.2.2 (CDC, Atlanta, GA; version 4/26/2004) database under four broad categories: background; methodology; report; and indicators. Sampling procedures were classified as reproducible if the population-based sampling defined a sampling frame and used probabilistic sampling, including proportional to population size (PPS) sampling if cluster sampling was used during the first stage, and all persons in the household within the stated age range were surveyed. Additional indicators for the quality of survey methodology were assessed, including essential steps of survey preparation and report writing.

Internationally-accepted standardized indicators were recorded as being included in the survey if the wording was the same or similar to the indicators in Table I. If information regarding survey methodology or indicators was not provided in the reports, it was recorded as non-reproducible or accepted indicators not used, respectively.

## Results

A total of 40 BSS or KAP surveys were identified, of which 31 (77.5%) were eligible according to the inclusion criteria. The 31 eligible surveys were undertaken between 1998 and 2005 in 14 countries. There were 12 countries (25 surveys) in Africa: Angola (1), Eritrea (1), Ethiopia (2), Kenya (2), Rwanda (2), Sierra Leone (3), Somalia (1), South Africa (1), Sudan (2), Tanzania (3), Uganda (5) and Zambia (2); and 2 countries (six surveys) in Asia: Nepal (2) and Thailand (4). Eight (25.8%) surveys were undertaken in conflict settings, nine (29.0%) in post-conflict settings and 14 (45.2%) in relatively stable countries hosting refugees. Among some of the eligible surveys, more than one affected population was studied; refugees were included in 28 (90.3%) surveys, IDPs in six (19.4%) surveys, returnees in three (9.7%) surveys and surrounding host populations in six (19.4%) surveys. The primary organizations responsible for the surveys were NGOs, (23 surveys, 74.2%), CDC four surveys (12.9%), a United Nations agency three surveys (9.7%) and one government survey (3.2%). The sample sizes of the surveys ranged from 148 to 7,484, with a mean of 1,261 and a median of 549 persons. Fourteen (45.2%) of the 31 surveys were classified as reproducible (see Table II). Surveys undertaken by NGOs were significantly less reproducible than those undertaken by non-NGOs (chi-square test,  $p=0.05$ ).

### *Survey methodology*

The number of households or persons refusing to participate in the survey was reported in nine (29.0%) surveys, absent households or persons reported in seven (22.6%) surveys and the use of household replacement was reported in nine (29.0%) surveys. Eighteen (58.1%) used purely descriptive analysis while 13 (41.9%) used both descriptive and comparative; for the latter, 11 (84.6%) of the 13 reports stated which statistical tests were used to make comparisons. Ten (32.3%) of the survey reports did not state which statistical software was used. Of the 21 (67.7%) reports that mentioned the type of statistical software, some used more than one type: EpiInfo (11), SPSS (8), SAS (3), CSPRO (2), SUDAAN (1) and SSP (1). Fourteen (45.2%) of the surveys had both a qualitative and quantitative component while 17 (54.8%) were solely quantitative.

In the written survey reports, 27 (87.1%) stated objectives, 10 (32.3%) stated they asked for informed consent, 17 (54.8%) pilot tested the questionnaire, six (19.4%) of 30 surveys back-translated the questionnaire (one survey was undertaken in English so did not need back-translation), 27 (87.1%) provided training for interviewers (range of 1–16 days with median of 3 days), 11 (36.7%) of 30 surveys had gender balance among interviewers (one survey required respondents to write answers on the questionnaire so there were no face to face interviews), nine (29.0%) stated definitions (e.g. high risk sex, non-regular partner), 13 (41.9%) stated limitations and biases, 23 (74.2%) stated conclusions

Table II. Sampling methodology and reproducibility for BSS and KAP surveys ( $N=31$ ).

<b>Sampling method</b>	<b>Frequency</b>	<b>Percent</b>
Random sampling	23	74.2%
Convenience	4	12.9%
Not mentioned	4	12.9%
<b>Total</b>	<b>31</b>	<b>100.0%</b>
<b>If random, what type?</b>		
Simple random	4	17.4%
Systematic	7	30.4%
Cluster sampling	8	34.8%
Not mentioned	4	17.4%
<b>Total</b>	<b>23</b>	<b>100.0%</b>
<b>If cluster sampling, was PPS used?</b>		
Yes	3	37.5%
Not mentioned	5	62.5%
<b>Total</b>	<b>8</b>	<b>100.0%</b>
<b>All eligible persons in household surveyed</b>		
Yes	31	100%
No	0	0
<b>Total</b>	<b>31</b>	<b>100.0%</b>
<b>Sampling frame</b>		
Yes	23	74.2%
No	8	25.8%
<b>Total</b>	<b>31</b>	<b>100.0%</b>
<b>Reproducibility</b>		
Yes	14	45.2%
No	17	54.8%
<b>Total</b>	<b>31</b>	<b>100.0%</b>

and recommendations based on study data, 16 (51.6%) provided references and 16 (51.6%) appended the questionnaire to the report.

### *Key indicators*

The majority of surveys reported the same or similarly worded internationally-accepted HIV indicators for prevention and misconception (except for the misconception question on the possibility of getting HIV from sharing a meal with someone who is infected with HIV); however, few reported disaggregated indicators by age and gender (Table III). The majority of surveys did not report the same or similarly worded internationally-accepted HIV indicators for practice and attitudes; few reported disaggregated indicators by age or gender (Table III).

Twenty-six (83.9%) of the surveys asked an HIV practice question with 14 (45.2%) asking the question that was the same as or similar to the internationally-accepted practice indicator that we chose (Table I); five (35.7%) disaggregated the indicator by gender and age (Table III). Twenty-one (67.7%) of the surveys asked HIV attitude questions with less than the majority asking at least one question that was the same as or similar to the internationally-accepted attitude indicators (Table I); few disaggregated by gender and age (Table III).

Table III. HIV/AIDS knowledge, practices and attitudes questions and indicators ( $N = 31$ ).

	Number*	Percent
<b>Knowledge</b>		
Did the study include <b>prevention</b> questions, even if they did not include the standard questions below?	26	83.9%
1) Sex with only 1 partner		
Same or similar wording	21	67.7%
Disaggregated by gender and age	6 ( $N = 20$ ) <sup>+</sup>	30.0%
2) Using condoms		
Same or similar wording	26	83.9%
Disaggregated by gender and age	6 ( $N = 25$ ) <sup>+</sup>	24.0%
Did study include <b>misconception</b> questions, even if they did not include standard questions below?	20	64.5%
1) Mosquito bites		
Same or similar wording	16	51.6%
Disaggregated by gender and age	3 ( $N = 15$ ) <sup>+</sup>	20.0%
2) Sharing a meal		
Same or similar wording	14	45.2%
Disaggregated by gender and age	5 ( $N = 13$ ) <sup>+</sup>	38.4%
3) Healthy-looking person can have/transmit HIV		
Same or similar wording	18	58.1%
Disaggregated by gender and age	4 ( $N = 17$ ) <sup>+</sup>	23.5%
<b>Practices</b>		
Did the study include practice questions, even if they did not include standard questions below?	26	83.9%
1) Condom at last sex with a high risk partner		
Same or similar wording	14	45.2%
Disaggregated by gender and age	5 ( $N = 14$ )	35.7%
<b>Attitudes</b>		
Did the study include attitude-related questions, even if they did not include standard questions below?	21	67.7%
1) Care for family with HIV/AIDS		
Same or similar wording	14	45.2%
Disaggregated by gender and age	3 ( $N = 14$ )	21.4%
2) Would buy fresh vegetables		
Same or similar wording	5	16.1%
Disaggregated by age	1 ( $N = 5$ )	20.0%
3) Teacher who is HIV+		
Same or similar wording	6	19.4%
Disaggregated by age	1 ( $N = 6$ )	16.7%
4) Would not want to keep secret		
Same or similar wording	7	21.4%
Disaggregated by gender and age	1 ( $N = 7$ )	14.3%

\*  $N = 31$  unless specified.

<sup>+</sup>  $N = 1$  less the total number of surveys with same or similar wording because one survey targeted one subpopulation of a specific gender and age.

## **Discussion**

Overall, the majority of surveys that met the inclusion criteria were of insufficient methodological rigor to be reproducible. Other important methodological issues, such as households or persons who were absent or refused to participate, as well as whether replacement of such households or persons occurred, were not stated in most of the reports. Sample sizes had a wide range and some may have been of insufficient size to be precise enough to interpret results or make meaningful comparisons with future surveys. The majority of questionnaires were not field tested or back-translated nor were qualitative methods used to complement the quantitative methodology used in many of these surveys. Only a minority of surveys obtained informed consent from participants. Few provided definitions of essential terms, such as high risk sex or non-regular partners. Although most of the surveys included training of surveyors, few reported gender balance of interviewers. All of the above methodological flaws inject sufficient biases into these surveys to make the most of them unacceptable.

The majority of the written reports lacked sufficient detail and structure to be analysed and interpreted by the reader in a meaningful way. Most reports provided objectives for the survey as well as conclusions and recommendations. However, few stated limitations and biases and only half appended the questionnaire to the report. Important methodological details were missing in many surveys, including information on how the sample size was chosen, the specifics of the sampling methodology and whether replacement was used. Most of the analyses were descriptive in nature with few reports using comparative statistics. The majority of reports used some variation of the internationally-accepted HIV indicators for knowledge (e.g. prevention and misconceptions) but only a minority used some variation of these indicators for practice and attitudes. The disaggregation by age or gender varied considerably among reports which led to difficulties in comparing results; furthermore, few studies reported indicators according to both gender and age.

There are limitations to this article. Despite an attempt to search as widely as possible in the published and grey literature, as well as to contact organizations known to undertake BSSs in conflict and post conflict settings, some surveys will have been missed. In addition, those included are not just BSSs but reproductive health KAP surveys with an HIV component. The latter may not contain as much detail on HIV as BSSs, however, this would neither affect the basic methodological weaknesses nor the absence of key internationally-accepted standardized HIV indicators. Some of the BSSs examined in this report were conducted before 2002 when the internationally accepted UNGASS indicators were developed; this together with the changing of indicators over time makes it difficult to interpret the usage of internationally-accepted indicators. Misclassification may have occurred because results were based on findings written in the reports reviewed. For those reports that omitted key methodological issues or results, the data were recorded in a negative fashion (e.g. if type of sampling was not mentioned, the survey was recorded as not employing random sampling).

BSSs are expensive and time consuming. In conflict and post-conflict settings, the costs of BSSs vary according to population and geographic size, but generally cost at least US\$50,000 for a typical refugee camp when conducted by qualified specialists (source: UNHCR based on 11 BSSs in five countries from 2004 to 2005). Anecdotally, some organizations having insufficient funding undertook surveys on their own or with inexperienced consultants; these surveys often had poor results. Therefore, adequate funding is needed before such surveys are undertaken.

BSSs collect crucial HIV/AIDS data to inform local and national interventions as well as for programme monitoring and evaluation, and for the allocation of scarce resources. Scientifically sound and reproducible studies with structured and detailed reports are needed. Our results showed that organizations that are specifically trained and have extensive experience in doing these surveys, such as CDC, undertook surveys and produced reports that were superior to those of NGOs. As was previously recommended for nutrition surveys in humanitarian emergencies, NGOs, governments, and UN agencies interested in undertaking BSSs in conflict and post-conflict settings must ensure that the process is developed and directed by qualified and experienced experts (Spiegel et al. 2004). This may require hiring organizations that specialize in undertaking such surveys. The decision to undertake such surveys should be made in a coordinated fashion with all relevant organizations, governments and affected populations. Persons writing such proposals should be aware of the financial, time and logistical constraints in correctly undertaking BSSs. Donors should only fund realistic and technically sound proposals. Systematic training and ongoing advocacy on these issues among NGOs, UN agencies, governments and donors is needed. An inventory of international experts that can assist in planning and undertaking field missions should be developed.

Unlike nutrition surveys in humanitarian settings (Spiegel et al. 2004), there is currently no standard questionnaire, methodology nor practical manual on how to undertake BSSs in conflict and post-conflict settings. Many BSSs are undertaken on a nationwide scale with large samples that require significant technical expertise and resources (e.g. demographic and health surveys with an HIV component). The FHI BSS guidelines for repeated behavioural surveys in populations at risk of HIV (Family Health International 2000) are often used as the standard manual for undertaking BSSs. However, this 350 page manual describes how BSSs can be undertaken in numerous different situations and is not designed to be a 'how to manual' such as those designed for nutrition surveys in humanitarian emergencies (Médecins Sans Frontières 1995, Save the Children 2004). Furthermore, conflict and post-conflict situations are unique and require different information from other populations (Spiegel 2004, UNHCR 2005). These include questions on displacement and interaction with surrounding host populations as well as sensitive questions on sexual exploitation and violence. Recognizing this need, the United Nations High Commissioner for Refugees in collaboration with the World Bank, UNAIDS and the Great Lakes Initiative on

AIDS are engaged in a process that will produce a BSS manual that can serve as a generic BSS tool for conflict-affected and displaced populations. This manual will contain practical sections on methodology, analysis and results, indicators, report writing as well as sample questionnaires that contain modules on pre-displacement, displacement and post-displacement/interaction with the surrounding host community. Emphasis on the latter and the need to undertake such surveys among both the displaced populations and surrounding host communities is emphasized. This effort will ultimately aid in the provision of integrated HIV/AIDS programmes for refugees and surrounding host populations (UNHCR 2005).

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