

# Developing survey-based indicators for national AIDS programmes

UNAIDS/MEASURE Evaluation Indicator Field Test Group [1]

In the early years of the HIV/AIDS epidemic, programme managers had little information about what interventions were likely to work in reducing the spread of the virus, and little idea how they might measure the success of their interventions, beyond simply tracking HIV or AIDS itself. What's more, it was widely believed that sensitive behaviors known to spread the virus, such as sex and drug injection, could not be reliably measured at all. While there was an urgent need to respond in any way possible, most program managers did not consider measurement of the success of the response to be high on their list of priorities.

Over the last decade, this thinking has changed. Much more is known about how HIV spreads through a population and what changes are needed to slow the spread. It has been amply demonstrated that people will answer questions about their sex lives, and there is growing evidence that their answers give a fairly reliable picture of trends in behavior over time.

As the body of knowledge about HIV grows, so does the interest in monitoring and evaluating the success of programmes designed to reduce the spread of infection and the impact that it has on families and communities. This interest comes from national governments, as well as taxpayers who want to be sure that the increasing amount of money invested in HIV prevention and care is being spent wisely.

Many tools already exist for monitoring HIV-related attitudes and behaviors. But the evolving epidemic has also brought new areas of concern and new approaches to preventing the spread of the virus and mitigating its effects. Some existing tools are outdated and need revising and improving to address these areas of concern and approaches. In some areas, entirely new measurement approaches must be devised.

MEASURE *Evaluation* has been working with national AIDS programmes and evaluation specialists in developing countries, as well as with colleagues in other international institutions and organizations, including the United Nations Joint Programme on HIV and AIDS (UNAIDS), Family Health International-IMPACT, the World Health Organization, the Centers for Disease Control and Prevention (CDC) and the United States Agency for International Development (USAID) [2], to help meet these needs. Together, this group of programmers

and evaluators has developed a framework for monitoring and evaluation AIDS programmes at a national level. They have identified indicators for most major areas of HIV prevention and care appropriate to different epidemic levels, and have devised tools to measure those indicators.

## *Field testing the questionnaire*

Obviously, no new tool can be considered useful until it has been tested. MEASURE *Evaluation* and its partners have, therefore, worked to test newly developed tools and indicators in several areas. Field tests of specific indicators and measurement instruments were conducted in Burkina Faso, Costa Rica, Nigeria, South Africa, Tanzania, Thailand and Uganda. Each of the field tests, conducted in 1998 and 1999, included interviews with around 100 respondents, 50 men and 50 women, in randomly selected households. The respondents were generally selected from low-income neighborhoods in urban areas, where multiple partnerships were thought to be common. After obtaining verbal consent, the interviewer administered a questionnaire-guided interview, followed by a short break in which the interviewer offered a soft drink to the respondent. In the second part an in-depth interview was conducted to discuss the questionnaire in general and to verify whether the survey questions had captured the knowledge and behaviors of the respondent correctly. In the analysis, data from the Zambia sexual behavior survey were also used if appropriate [3].

The results of the field tests were discussed at an international meeting and the lessons learned during the field tests were used to amend the proposed indicators and measurement instruments. The amended instruments and indicators were incorporated into the current edition of the National AIDS Programmes: A Guide to Monitoring and Evaluation, which can be found on the Measure *Evaluation* Web site [4].

This issue of the *Bulletin* describes the results of the field tests in three areas: knowledge about the existence, transmission and prevention of HIV; sexual behavior; and stigma and discrimination related to HIV and AIDS.

## Notes

[1] The UNAIDS / MEASURE Evaluation indicators field test group consisted of

- Wasanna Im-Em, Institute for Population and Social Research, Mahidol University, Bangkok, Thailand
- Xoli Mahlalela, EQUITY Project, Management Sciences for Health, East London, South Africa
- Nicolas Meda, Cente MURAZ/OCCGE, Bob-Dioulasso, Burkina Faso
- Eiliana Montero Rojas, School of Statistics, University of Costa Rica, San Jose, Costa Rica
- Gernard Msamanga, Department of Community Health, Muhimbili College of Health Sciences, Dar es Salaam
- Stella Neema, Makerere Institute for Social Research, Makerere University, Kampala, Uganda;
- Julie Victor-Ahuchogu, Family Health International, Lagos, Nigeria
- Elizabeth Pisani, consultant, Nairobi, Kenya
- Bernhard Schwartlander, UNAIDS, Geneva, Switzerland
- Bates Buckner, Amy Cunningham, Ties Boerma, MEASURE Evaluation, Carolina Population Center, University of North Carolina, Chapel Hill, USA.

[2] Funding for the field test was provided by UNAIDS, the Africa Bureau/Sustainable Development of USAID and the Global HIV/AIDS Bureau of USAID through the MEASURE Evaluation project.

[3] UNAIDS. National AIDS programmes: a guide to monitoring and evaluation. UNAIDS document 00/17E. Geneva. June 2000.

[4] Zambia Sexual Behavior Survey 1998. Central Statistical Office, Lusaka, Zambia, and MEASURE Evaluation, University of North Carolina at Chapel Hill. April 2000. Chapel Hill, NC, USA.

## How much do people really know about HIV?

UNAIDS/MEASURE Evaluation Indicator Field Test Group [1]

- ✓ A field test in seven countries was conducted to develop HIV-prevention knowledge indicators
- ✓ Responses obtained by spontaneous questions or by prompted questions may have multiple biases, but prompted questions appear to be more suitable for monitoring trends over time.
- ✓ The field test resulted in two composite indicators of knowledge, both based on prompted questions on correct prevention knowledge and misconceptions.

In the early days of the HIV epidemic, “raising awareness” about AIDS was seen as a crucial task. If people knew about this fatal disease and how it was transmitted, it was reasoned, they would certainly take steps to avoid being infected. So it was that many early surveys related to HIV began with “Have you heard of a disease called AIDS?” and centered around finding out what people knew about transmission and prevention of HIV.

### *Knowledge indicators: the status quo*

Since 1994, the standard indicator recommended by the World Health Organization (WHO) to track public awareness of AIDS and knowledge about AIDS has been the number of people citing at least two acceptable ways of protection from HIV infection, divided by the total number of people aged 15-49 surveyed.

People were asked in a survey whether “People can protect themselves from HIV/AIDS” in certain ways. They were then read a list of statements and were prompted to say whether each one was true or false. The prevention strategies considered “acceptable” were “staying with one faithful partner” and “using condoms during sexual intercourse.” Responses to false statements included in the list (such as avoiding public toilets) were not included in any indicator.

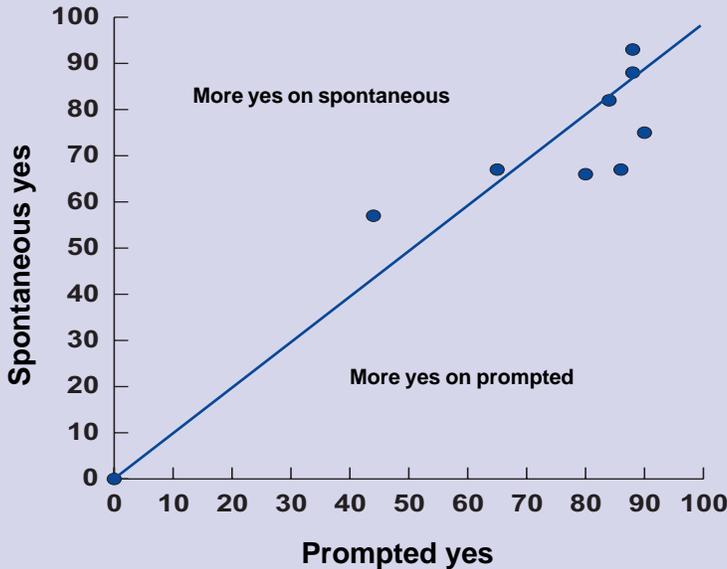
Some other surveys took a similar approach, but included abstinence among the correct methods for avoiding HIV. In addition, some surveys simply asked how HIV could be avoided and recorded spontaneous responses, rather than prompting for responses.

### *The problem*

Two decades into the epidemic, several things are clear. First, virtually everyone in countries badly affected by HIV knows about AIDS and the virus that causes it. There are still small pockets of ignorance, principally among young and old women in rural areas, but knowledge of HIV is probably better than knowledge of any other health condition. Secondly, knowing that abstinence or condom use prevents HIV does not automatically translate into safe sexual behavior, any more than knowing that smoking causes lung cancer stops teenagers from taking up smoking. Third, correct knowledge absorbed from public information campaigns is mixed up with incorrect knowledge based on rumor, superstition, traditional belief systems and occasionally even deliberate misinformation campaigns by those opposed to condom use or other HIV-prevention strategies.

These problems call into question the value of knowledge indicators. In the first place, it hardly seems worth measuring something that goes from 96.1% to 97.2%. That is especially true if that knowledge doesn’t seem to have any effect on people’s behavior anyway, since it is how people behave, and not what they know, that drives the HIV epidemic. How then, can the attitudes and thinking processes that drive people’s behaviors (in other words, the difference between what people “know” and what they really believe) be measured?

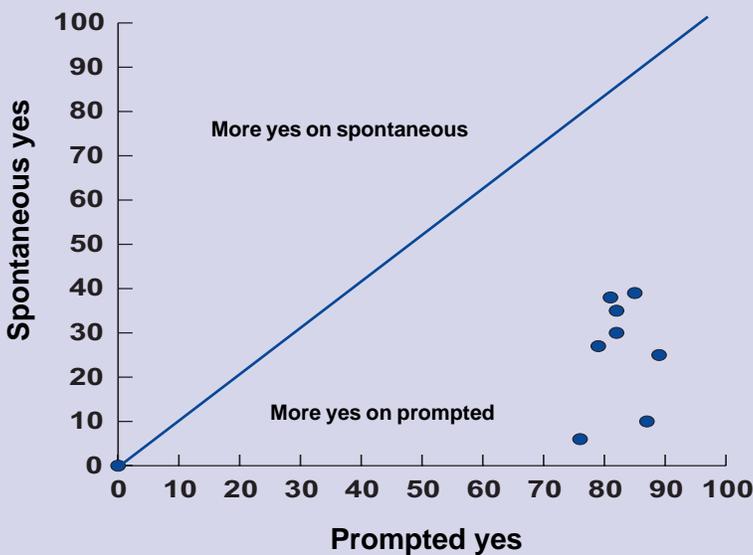
Figure 1. Can people protect themselves against the AIDS virus by using a condom every time they have sex?



### To prompt or not to prompt

The desire to measure what people believe rather than what they know sparked a lengthy discussion in the evaluation field over whether knowledge questions should be prompted or not. Some evaluation specialists believed that spontaneous answers were more likely to represent the prevention options that people believed in, that is, those that they think are relevant to and possible for them. Others thought that people's spontaneous answers would be affected by the attitude of the interviewer. More important for monitoring purposes, interviewer variability may occur in coding the spontaneous responses. The extent to which the interviewer patiently probes different modes ("Any other way of prevention?") and the interpretation of the answers into pre-coded answers can vary between surveys and between interviewers. Whether the respondent had to answer 50 or 100 questions prior to this question, may also affect the ultimate answers. All of these problems can distort survey results and make it difficult to compare results across surveys or look at trends over time.

Figure 2. Can people protect themselves against the AIDS virus by having one uninfected partner who also has no other partners?

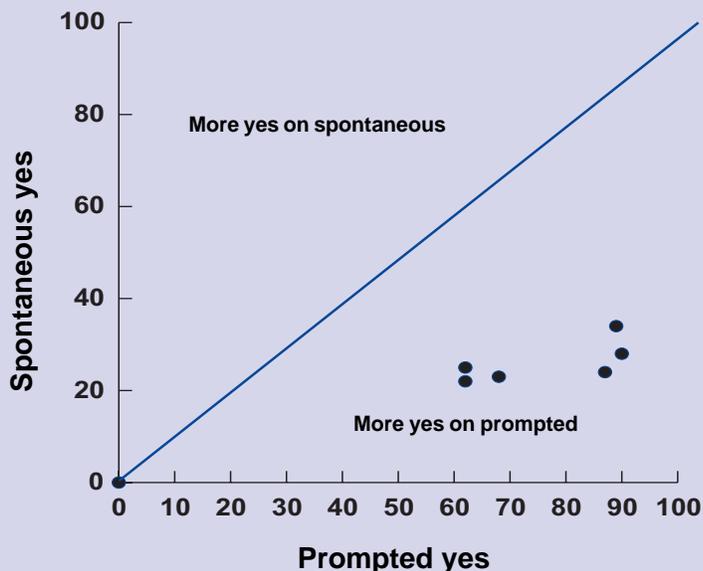


### The right word

In many countries, people's knowledge about HIV has reached quite sophisticated levels. That affects the responses they give to knowledge questions. Consider the relatively simple question: Can you avoid HIV by using condoms? Correct answer: Yes. Or is it? What if the condom breaks? What if you are already living with HIV? What if there is no chance of your using a condom because your husband refuses? The more people know about HIV, the more important the exact wording of knowledge questions becomes, if ambiguities are to be avoided and trends over time are to emerge clearly.

HIV is such a complex subject that it does not necessarily follow that, as correct knowledge increases, incorrect knowledge decreases. People can hold correct and incorrect beliefs about the epidemic simultaneously, and the wrong may well override the right. For example, if you believe that HIV can be transmitted by mosquitoes and you live in an area where you are bitten by mosquitoes daily, it hardly seems worth using a condom on the

**Figure 3. Can people protect themselves against the AIDS virus by not having sex at all?**



occasions you have sex, just to protect yourself from that additional risk of contracting HIV. As awareness campaigns achieve their goals of educating people about the realities of HIV transmission, they may have to turn their attention increasingly to stomping out rumors and wiping out incorrect beliefs which threaten to undermine their previous successes.

### Field test findings

The field tests were designed to look at some of these issues. The difference between prompted and unprompted answers was explored in questionnaires that asked first for spontaneous answers, then prompted the respondent to declare various prevention options true or false, in questions phrased “Can people protect themselves from the AIDS virus by ...”. In-depth follow-up interviews explored people’s reasons for giving certain answers, to help ascertain whether a straightforward interpretation of data was possible.

Incorrect information was also included in the promoted questions. One misconception – people cannot get infected by a person who looks healthy – was common to all field tests. The others were specific to the country where the field test took place and were developed in pre-test research to reflect locally common beliefs. This research was especially impor-

tant because the survey team was keen to avoid creating rumors and misconceptions which had not previously existed in these locations. A few misconceptions, including infection through a mosquito bite and infection through witchcraft, were common across several countries.

These field test findings highlighted once again the importance of the wording of questions. Following the field test results, the questions that began with, “Can people protect themselves from the virus that causes AIDS...?” were reformulated to read, “Can a person reduce their risk of contracting the virus that causes AIDS...?”

HIV-related knowledge, as measured by the existing WHO indicator, was high in most countries. When people disagreed that “correct” methods were protective against HIV, in-depth interviews generally found that this was because knowledge was higher than anticipated, and so people were entering into the “it depends” mode. Another striking finding was the difference in responses according to whether questions were prompted or spontaneous, except, encouragingly, when it came to condom use.

### Comparing prompted and spontaneous responses

Figures 1 to 3 compare correct and prompted responses for different prevention strategies in all of the field test countries. If there were exact agreement between the two, the dots would all fall along the black line. When dots fall under that line, it means that people were more likely to give that response when prompted than they were to mention it spontaneously.

Condom use was the most common spontaneous response in all countries. There was good agreement between spontaneous and prompted answers, suggesting that it does not matter how this method of protection is asked. The line in Figure 1 indicates all cases in which there would be perfect agreement between the spontaneous answers and the prompted question. The points are clustered near the line, indicating a good agreement between both methods of assessing knowledge.

There was far less agreement about other prevention strategies, with people generally more likely to give a “correct” response when prompted than spontaneously. Significantly fewer than half of all respondents in any country volunteered abstinence or mutual faithfulness as an effective prevention strategy, although when prompted up to nine in 10 said these were indeed effective strategies.

## Spontaneous

In what ways can people reduce their risk from getting infected with HIV?

Any other ways?

(CIRCLE ALL THAT ARE MENTIONED.  
MORE THAN ONE ANSWER IS POSSIBLE.  
DO NOT READ OUT THE WAYS.)

- USE CONDOMS ..... A
- HAVE FEWER PARTNERS ..... B
- BOTH PARTNERS HAVE  
NO OTHER PARTNERS ..... C
- NO CASUAL SEX ..... D
- NO SEX AT ALL ..... E
- NO COMMERCIAL SEX ..... F
- AVOID INJECTIONS WITH  
CONTAMINATED NEEDLES ..... G
- AVOID BLOOD TRANSFUSIONS ..... H
- OTHER (SPECIFY) ..... X
- DON'T KNOW ANY ..... Z

## Prompted

Can people reduce their chances of getting the AIDS virus by using a condom correctly every time they have sex?

YES.....1      NO..... 2      DON'T KNOW..... 3

Can people reduce their chances of getting the AIDS virus by having only one sex partner who has no other partners?

YES.....1      NO..... 2      DON'T KNOW..... 3

Can people protect themselves against the AIDS virus by not having sex at all?

YES.....1      NO..... 2      DON'T KNOW..... 3

The prompted question generates more than twice as many affirmative responses as the spontaneous question (Figure 2). Data from the in-depth interviews with the same respondents suggest that the higher scores are in fact a more accurate reflection of respondents' knowledge than are the lower levels based on a spontaneous listing. Many people indeed believe that faithfulness of both partners is a prevention method. Of course, even for the prompted question, faithfulness to a single partner may not be very effective if the partner is HIV infected. Following debate about whether the prompted question should specify whether or not the partner is HIV negative, the price of ending up with an awkward question was considered too high.

Similarly, for abstinence, most people agree that abstinence protects (this question was still asked in the 'old' way), but less than one-fourth spontaneously mentioned abstinence as a prevention method (Figure 3). It was decided to exclude abstinence as a "correct" method of prevention used in the knowledge indicator. With the exception of young people, it is rarely used as a primary HIV prevention method among adults who are already sexually active. In addition, people who know that HIV is sexually transmitted would almost certainly also know that not having sex can reduce the risk of transmission. Negative responses on this item are more likely to result from people believing that abstinence is not feasible, rather than from their believing that abstinence does not provide effective protection.

Very few people spontaneously volunteered incorrect methods of HIV prevention. However when prompted for incorrect, but locally common beliefs that had come up in pre-test research, significant proportions of people were found to have erroneous beliefs. As with correct knowledge, the question remains – if people did not hold these beliefs strongly enough to mention them without prompting, is it likely that their behavior would be shaped by these misconceptions?

### *Resulting indicators*

The following two general knowledge indicators were chosen and included in the UNAIDS Guide for monitoring and evaluation of national AIDS programs [2].

#### **Knowledge Indicator 1**

**The percentage of all respondents who, in response to prompted questions, say that a person can reduce their risk of contracting HIV by using condoms or having sex only with one faithful, uninfected partner**

#### **Knowledge Indicator 2**

**The percentage of all respondents who, in response to prompted questions, correctly reject the two most common local misconceptions about AIDS transmission or prevention, and who know that a healthy-looking person can transmit AIDS**

These field tests have shown that careful wording of questions is essential. They have indicated, too, that prompted responses give higher rates of “correct” knowledge than unprompted responses. Details on the indicators and tools can be found in the UNAIDS guide on monitoring and evaluation [2].

## Notes

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- Wasanna Im-Em, Institute for Population and Social Research, Mahidol University, Bangkok, Thailand
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[2] UNAIDS. National AIDS programmes: a guide to monitoring and evaluation. UNAIDS document 00/17E. Geneva. June 2000.



## Measuring risky sex and condom use

UNAIDS/MEASURE Evaluation Indicator Field  
Test Group [1]

- ✓ **A field test in seven countries was conducted to assess the feasibility and utility of a revised approach to soliciting information on sexual partnerships and condom use.**
- ✓ **It was found to be more appropriate and feasible to define higher risk partnerships as non-marital, non-cohabiting partnerships, rather than the previously used non-regular partnerships (where non-regular referred to the duration of the partnership).**
- ✓ **Collecting information on partnerships worked well in most settings and there is some evidence that these data may indicate higher levels of reporting of higher risk partnerships.**

Discussion about the social and economic determinants of HIV continues: poverty, inequality between men and women, marginalization, cultural norms, and even corruption have been fingered as contributing to the spread of AIDS. But it is important to be absolutely clear about one thing — HIV is spread through sex without condoms. Any number of other factors may influence who has sex with whom and whether they use condoms, but the act that spreads the virus, in the overwhelming majority of cases, is an act of unprotected sex. And, it is only changes in patterns of sex and condom use that will change the course of the epidemic.

Most HIV prevention programs aim to reduce unprotected sex, especially between partners who also have sex with other people. The success of these initiatives can most easily be monitored by measuring changes in sexual behavior. The measurement of sexual behavior and condom use has, therefore, become central to monitoring and evaluation of AIDS prevention programs.

### *The status quo*

Indicators to date have concentrated on partnerships most likely to be at risk. These were defined by the WHO as any sexual relationship that lasted or was expected to last for less than a year, and labeled “non-regular partnerships” [2]. The WHO-defined indicator for risky sexual partnerships is the number of people surveyed who report any non-regular partnership in the last year, divided by the number of people surveyed who report any sex in the last year.

The questionnaire asked first whether the respondents have ever been married and then whether they have any regular partnerships other than with their spouses. A question is also asked about whether a condom was used the last time they had sex with a spouse or regular partner. The respondents are next asked whether they have had any other sex partners (partners with whom the respondent had sex for less than 12 months) in the last 12 months, and if so how many. A question about the use of a condom with the last non-regular partner is also asked.

The condom-related indicator recommended by WHO has been the number of people surveyed who report using a condom at last sex with a non-regular partner, divided by the number of people surveyed who report any sex with a non-regular partner in the last year.

### *The problems*

As experience with the WHO questionnaire grew, it became clear that many people were confused by the definition “non-regular partner.” Even more problematic, was the finding that the definition was not capturing all high-risk partnerships, as it was intended to do. This is because, in some cultures, people have several simultaneous, but relatively long-lasting partnerships outside marriage. This is clearly a risk for HIV, since these partners are likely also to have other partners, but this situation was not included as risky under the WHO definitions.

Another problem became apparent as sexual behavioral surveys became more common. People don’t generally like to admit to high numbers of partners outside marriage, because non-marital sex is viewed by moralists in many societies as unacceptable. Men sleeping around is considered bad, women sleeping around is considered inexcusable in most countries. So most people, especially women, tend to underreport their sexual partners. This may be especially true if respondents are asked directly to report how many people they have had sex with in the past year.

The explosive growth of HIV in many countries has made it clear that there has been more sexual networking going on than was previously reported. The challenge for evaluation has been to improve the level of reporting of casual partnerships. Any such improvement would bring its own problems, however. Monitoring tends to center on measuring changes in behavior or other factors over time. As long as under-reporting is consistent over time (and does not, for example, become more pronounced as HIV-prevention campaigns increase the disapproval associated with an active sex life), trends will not be affected. You may be measuring far less casual sex than is actually taking place, but if the level of sex falls, you will still see the change. But if new methods suddenly improve reporting of multiple sex partners, it will disrupt trends over time. Of even greater concern, without elaborate explanations about the changes in methods, it will look as though prevention programs are failing and risky sexual partnerships are actually on the rise.

The questions on the number of partners in the last year have focused on the individual and not so much on the type and characteristics of partnerships. However, there is increasing evidence that the type of sexual mixing matters a lot in the spread of HIV, and that interviews can actually collect data

on partnership characteristics (e.g. type and duration of relationship, age, residence and marital status of partner).

Condom indicators have been found to be relatively robust. In countries with very high levels of HIV prevalence, however, there has been some concern that efforts should be made to measure consistent condom use rather than condom use at last sex. This is because in situations where the probability that any sex partner is infected with HIV is high, occasional condom use cannot be considered safe behavior.

### *New approaches*

The first challenge was to clear up the confusion created by the “non-regular partner” definition and replace this definition with something that better captured the levels of risk inherent in different partnerships.

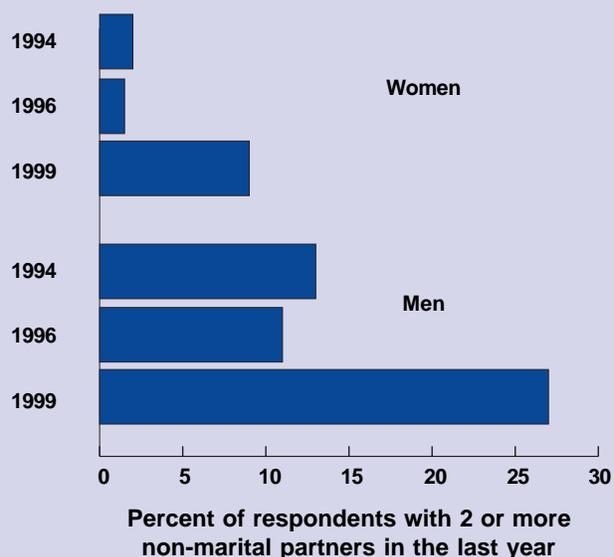
The proposed solution was to move to a definition based not on duration of relationship, but on who lives where. If a man and a woman live together, that relationship is likely to be their primary and most stable sexual relationship. It is believed that HIV transmission is less likely to take place in such relationships than in relationships where partners are living apart and have more opportunity to have sex with other people.

The new definition used for a “regular” partner was a partner to whom you are married or with whom you are living (cohabiting). Any other sex partner is considered the equivalent of a “non-regular” partner, and deemed to be a relatively high-risk partner for HIV infection.

The problem of under-reporting of sex partners is more difficult to attack. It was thought that asking, in a non-judgmental way, about specific partnerships might yield better results than asking general questions about the number of partners. A questionnaire was, therefore, developed asking about the last sexual partner, then the sexual partner before that, then the sexual partner before that. For each partner, details of the relationship to that person and some details of sexual history, including condom use at last sex, are included.

Measures of consistent condom use were discussed at great length. Ultimately, however, no indicator of consistent condom use was identified. This is because people are far more likely to give accurate answers about specific events than about general principles. Ask a young, single man if he uses condoms all the time and he may well say yes. But ask him if he used one last Saturday night, when his soccer team won and he went out on the town after several beers, and he may not be so positive. The advantage of the “status quo” measure of condom use, which essentially asks about condom use at last risky sex, is that while it refers to a specific event, it is bound to rise

**Figure 1. Sexual behavior reporting by men and women in different surveys in Tanzania, 1994-1999**



if consistent condom use rises. The existing indicator was therefore retained and no changes were field tested.

### Field test results

There did not seem to be any major difficulties with the change of definitions aimed at distinguishing risky from less risky sexual relationships. However it is worth noting that in many countries, especially in Africa, labor migration is the norm and married partners can live apart for many months of the year. In these cases, it is highly likely that one or both partners will have other partners over the course of the year, and it is not clear why these relationships should be considered much less risky than non-cohabiting relationships.

Between 20% and 80% of men reported a non-marital, non-cohabiting partner in the past year; 2% to 52% of women did so in the field test sites. Overall 10-60% of men and 2-50% of women reported two or more sexual partners in the last year.

The change of questionnaire may improve reporting of multiple sexual partnerships, although subsequent in-depth interviews suggest that some under-reporting still persists in surveys. In the Tanzania Reproductive and Child Health Survey 1999 (TRCHS 1999), the questions were asked in the same way (asking about partnerships), resulting in a much higher

proportion of men and women reporting multiple partnerships in the last year than in the Tanzania DHS 1996 or Tanzania KAPS 1994, in which the question was asked in the conventional way (number of partners in the last year) (Figure 1). Since it is unlikely that such a dramatic increase occurred in the period 1996-1999, the way of asking about sexual partnerships may be responsible for an important part of the difference.

One of the disadvantages of the three-partner approach to questioning is that it lengthens the interview considerably for people with more than one partner and subjects them to repetitive questioning about the details of their sex lives. Researchers conducting the field tests reported some impatience on the part of respondents. Many respondents said they were embarrassed by the subject matter but persuaded by the professionalism of the interviewers to participate in the studies. In other such research studies, similar questionnaire have included questions on the last 8 partnerships in the past year [2].

### Resulting indicators

#### Sexual Behavior Indicator 1: Higher risk sex in the last year

**The percentage of respondents who have had sex with a non-marital, non-cohabiting partner in the last 12 months of all respondents reporting sexual activity in the last 12 months**

#### Sexual Behavior Indicator 2: Condom use at last higher risk sex

**The percentage of respondents who say they used a condom the last time they had sex with a non-marital, non-cohabiting partner, of those who have had sex with such a partner in the last 12 months**

Details on the indicators and tools can be found in the UNAIDS guide on monitoring and evaluation [3].

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[2] Evaluation of national AIDS programme: A method package 1. Prevention of HIV infection. World Health Organization. Global Programme on AIDS. World Health WHO/GPA/SEF/94.1. Geneva.

[3] UNAIDS. National AIDS programmes: a guide to monitoring and evaluation. UNAIDS document 00/17E. Geneva. June 2000.

## The hidden truth: trying to measure HIV-related stigma

*UNAIDS/MEASURE Evaluation Indicator Field Test Group [1]*

- √ **Measuring levels and trends in stigma and discrimination in household surveys is difficult because of reporting biases.**
- √ **The field test resulted in one indicator of stigma based on four carefully phrased questions.**

Since AIDS was first identified at the end of the 1970s, it has been a magnet for stigma and discrimination. This is partly because HIV is spread by sexual and drug-taking behaviors that many people are happy to practice, but readily disapprove of publicly.

Stigma, and the discrimination that results when people act on stigma, can make life miserable for people living with HIV. The fear of stigma discourages people who know they are infected with HIV from seeking the care and moral support that everyone needs when they are living with a terminal illness. Infected people may even be reluctant to share information about their status with their sexual partners and families, making it difficult to prevent further infection or to plan a secure future for surviving children and family members. Fear and stigma promote denial, dissuading people from finding out whether they are infected, even in countries where HIV infection is approaching a norm among sexually active adults.

It is widely believed that a reduction of stigma would result in more openness about HIV, acting as a wrecking ball for the denial that stands in the way of more successful HIV prevention and care. But while HIV-related stigma is widely acknowledged to exist, efforts to quantify it have been elusive.

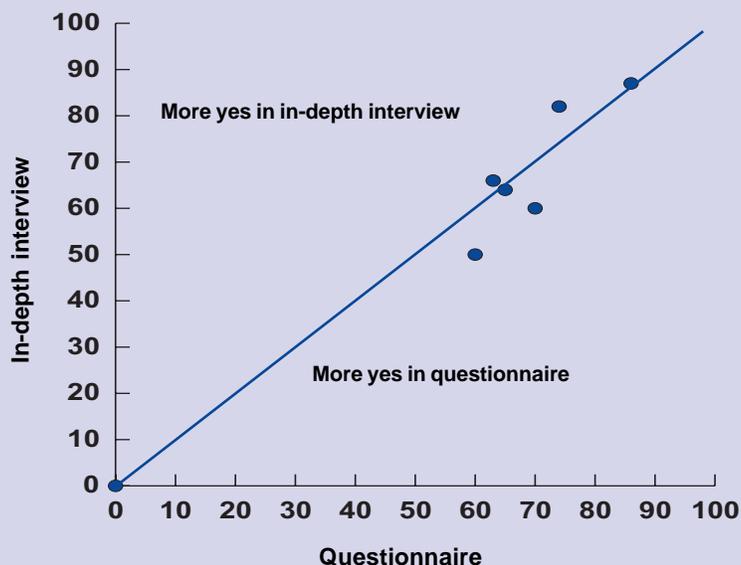
### *Indicators of stigma: the status quo*

Standardized surveys going back to the late 1980s have attempted to measure HIV-related stigma by asking people about their attitudes to people living with AIDS. The most common questions, included in an international survey series conducted by the World Health Organization in the late 1980s and early 1990s, were: Would you be willing to take care of a family member with AIDS? Should people living with HIV be entitled to keep their status a secret? Should people with HIV who work in an office or factory be allowed to continue their work? And should people with AIDS receive less, the same or more health care than other seriously ill people? While it was proposed that answers to these questions be compiled into an indicator of stigma, the indicator was never widely used.

### *The problem*

The biggest problem with measuring stigma is stigma itself. Even where HIV is very, very common it is rarely acknowledged on a personal level, so it is hard to ask about real events and experiences. Hypothetical questions are, however, more likely to draw “desirable” answers than questions about real events. And since stigma is hard to define, it is not always obvious which answers can be considered stigmatizing. If someone says that a person with HIV is not entitled to keep their status a secret, for example, is that necessarily stigmatizing or does it perhaps reflect a concern for the rights of sexual partners to protect themselves against infection? These

Figure 1. Percent who say an HIV-infected teacher should continue teaching:  
Comparison of Questionnaire and In-Depth Interview



## Field test results

In attempting to improve the measurement of stigma, MEASURE *Evaluation* and its partners modified an existing approach and also tried something new. It was decided to try the survey approach again, but to modify the questions asked, to give a better sense of stigma by using examples that people were likely to encounter in their own lives. The yes/no/don't know questions used in the field tested population surveys were

- If a relative of yours became sick with the AIDS virus, would you be willing to care for him or her in your household?
- If a teacher has the AIDS virus but is not sick, should he or she be allowed to continue teaching in school?
- If you knew that a shopkeeper or food seller had the AIDS virus, would you buy food from them?
- If a member of your family got infected with the AIDS virus, would you want it to remain a secret?
- Should people with AIDS receive less, the same or more health care than other seriously ill people?

As with the questions on sexual behavior, it was found that the attitudes people expressed depended very much on the exact wording of the question. In one country, for example, very high proportions thought that HIV-infected teachers should be fired. In-depth questioning determined that this was because of a recent wave of reports about teachers raping schoolgirls.

Similarly with food sellers, people were concerned food vendors might cut themselves while cooking and contaminate the food with their HIV-infected blood. The questions were altered again following the field tests. The recommended questions now concern female teachers and vendors of unprepared food such as vegetables. This raises other concerns – the more restrictions and qualifications a question has, the more respondents may feel they are being herded into a “desirable” answer.

The levels of correspondence between the answers given in the questionnaire-guided interview and the in-depth interview were high. Figure 1 shows that the percentage of respondents who said that an HIV-infected teacher should continue teaching in the questionnaire was the same as in the in-depth interview.

equations become more complex as HIV becomes more widespread in the population.

When a survey records stigmatizing attitudes, it is likely that these attitudes actually exist. However if survey respondents give answers that indicate that they are not likely to discriminate against people with HIV, the picture is less clear. It may mean that attitudes towards people with HIV are supportive or it may just mean that people are not willing to admit publicly to their discriminatory attitudes, just as they might be unwilling to admit to common, but widely reviled attitudes, such as racism. Changes over time in reported stigmatizing attitudes may reflect real changes or just a growing willingness or unwillingness to tell the truth. Campaigns to “break the silence” about HIV might have more effect on diminishing the willingness to report stigma than they have on wiping out the stigma itself. It is worth noting that, in some settings, even a growing awareness that it is “not nice” to openly discriminate against people with HIV might be considered a step forward, although it is doubtful whether less expressed stigma translates into less discrimination.

The value of including the questions on willingness to care for a family member with AIDS and equity in access to care for AIDS patients was limited. In all settings, nine out of 10 respondents were willing to care for a sick family member and nearly all respondents thought access should be equal or better for AIDS patients.

The field tests revealed little about the relationship between expressed attitudes and actual stigma. However, there was some indication that people were more willing to report supportive attitudes than they were to act on them. In one country, respondents who said HIV-infected teachers should continue in their jobs also, in in-depth questioning, said if an infected teacher was retained, they would send their own children to a different school.

Some research has suggested that women with HIV/AIDS are treated worse and viewed more harshly than men with HIV/AIDS. In that case, it is necessary to use gender-specific questions about stigma and discrimination. However, in some surveys, the “willingness to care” question has been asked for male and female relatives and no difference was found.

## *Resulting indicator*

### **Stigma and Discrimination Indicator 1**

**The percentage of all people expressing accepting attitudes towards people with HIV, of all people surveyed aged 15-49**

It is a composite indicator. Only a respondent who reports an accepting or supportive attitude on all four of these questions listed in bold enters into the numerator. The denominator is all people surveyed.

Details on the indicators and tools can be found in the UNAIDS guide on monitoring and evaluation [2].

## *Notes*

[1] The UNAIDS / MEASURE Evaluation indicators field test group consisted of:

- Wasanna Im-Em, Institute for Population and Social Research, Mahidol University, Bangkok, Thailand
- Xoli Mahlalela, EQUITY Project, Management Sciences for Health, East London, South Africa
- Nicolas Meda, Cente MURAZ/OCCGE, Bob-Dioulasso, Burkina Faso
- Eiliana Montero Rojas, School of Statistics, University of Costa Rica, San Jose, Costa Rica
- Gernard Msamanga, Department of Community Health, Muhimbili College of Health Sciences, Dar es Salaam
- Stella Neema, Makerere Institute for Social Research, Makerere University, Kampala, Uganda;
- Julie Victor-Ahuchogu, Family Health International, Lagos, Nigeria
- Elizabeth Pisani, consultant, Nairobi, Kenya
- Bernhard Schwartlander, UNAIDS, Geneva, Switzerland
- Bates Buckner, Amy Cunningham, Ties Boerma, MEASURE Evaluation, Carolina Population Center, University of North Carolina, Chapel Hill, USA.

[2] UNAIDS. National AIDS programmes: a guide to monitoring and evaluation. UNAIDS document 00/17E. Geneva. June 2000.



## Estimating the number of sex workers in a city: an experiment with the “capture-recapture” method

*Sharon Weir and Elizabeth Pisani*

- ✓ **Estimating the size of the sex worker population is important for understanding the dynamics of the AIDS and other sexually transmitted diseases epidemics and for interventions.**
- ✓ **The capture-recapture method has been used in epidemiologic and other studies and can be used to estimate the size of populations.**
- ✓ **In Bulawayo, Zimbabwe, the method seriously underestimated the number of sex workers compared with a census of bars.**
- ✓ **The capture-recapture method could have provided a more accurate estimate if fairly simple additional information had been collected to correct for the underestimate.**

More than two-thirds of the 36 million people living with HIV in the world live in sub-Saharan Africa. The overwhelming majority of them were infected during unprotected sex. Sex workers, who have a high turnover of partners, can contribute disproportionately to this spread, especially early on in the epidemic. Promoting safe sex among sex workers and their clients is, therefore, a critical part of a comprehensive HIV-prevention strategy. But, it is difficult to plan prevention programs efficiently without information about who sells sex and who buys it, and under what circumstances.

This information is not, however, always easy to come by. Sex work is illegal in many countries and in most it is highly stigmatized. Yet, good estimates of the total population of sex workers are essential, both to plan programs and to evaluate whether they are working.

A study in Zimbabwe’s second largest city, Bulawayo, estimated the size of the sex worker population using a sampling method known as “capture-recapture.” The study evaluated how well capture-recapture worked by comparing the results of this method with a straightforward count of sex workers found in bars in the city.

### *Counting fish in a lake*

Capture-recapture was first developed as a way to estimate wildlife populations. Using an example from the animal world, such as an estimate of the number of fish living in a large lake, is probably the best way to explain how it works. A certain number of fish are caught, tagged and thrown back into the lake. Some days later, a similar number of fish are caught and examined for tags. The likelihood of the same fish being caught twice will depend on the overall number of fish in the lake. That number can be calculated from the proportion of fish caught the second time around that were tagged. For example, if 1000 fish were caught and tagged, and then later, 20 percent of a second catch of 1000 were found to be tagged, the capture-recapture estimate of the total population of fish is 5,000 ( $200 = 20\% \text{ of } 5000$ ).

For this method to work well, certain conditions have to be fulfilled. First, the population has to be defined and unchanging, which is the case with fish in a lake – this condition is known as “population closure.” Second, there has to be an equal chance of capturing each individual in the population (known as “equal catchability”). Third, we have to be able to assume that once a subject is tagged, they remain tagged (known as “mark integrity”).

## Sex workers and bars

Of course people are often more complicated than fish, and it is not clear to what extent these conditions hold in human populations, particularly hard-to-reach populations, such as sex workers. The study focused on sex workers who work out of 56 bars well known in Bulawayo for sex worker activity. In fact, according to sex workers themselves, who assessed each bar, all women at these 56 bars could be assumed to be sex workers. So these 56 bars in Bulawayo functioned in this study like the “lake.” However, it is clear that not all sex workers were in one of those bars on the nights when the capture-recapture interviews took place, so the principle of population closure was not entirely fulfilled.

Of the 56 bars, the study picked the three largest and 12 others at random, with a probability of being selected commensurate with their size. Interviewers visited the same 15 bars two Saturday nights in a row, interviewing over 1,300 women each night. The women interviewed the first night were “tagged” by giving them a pen or a calendar: during the second interview they were asked whether they had been interviewed a week earlier, and asked to describe the gift they were given as a tag. There was no indication that women lied about earlier interviews or the presents they received, so it seems as if the condition of mark integrity was largely fulfilled.

## Unequal catchability

The principle of equal catchability was, however, more problematic. For this principle to hold true, sex workers would have to circulate more or less randomly between all 56 bars in the city. And yet sex workers, just like their clients, are likely to be people of habit, sticking to bars close to their homes or the locations where they have sex, bars where they are known or where their regular clients like to drink. This was anticipated in the study design, and a series of questions were included in the interview so that information from sex workers identified twice could be linked, to determine whether they were “captured” in the same or in different bars. Unfortunately, many women thought these questions (which included information such as place of birth and name of the oldest child) might be used to identify them, so they refused to answer. This meant that information could not be linked between interview rounds and it was not possible to adjust for people’s propensity to visit the same bar repeatedly.

The principle of equal catchability was further compromised by the selection of the same 15 bars both nights. If women circulated randomly between bars, this would have made little difference, but since it appears they did not, returning to the same bars violated the principle of equal catchability. To the extent the women returned to the same bar, the capture-recapture estimate is an estimate of the number of sex workers at these 15 bars rather than at all 56 bars.

## Comparing different counts

It is perhaps not surprising, then, that the capture-recapture estimate was lower than the number of women counted at all 56 bars in the city. Overall, 1,381 women were interviewed the first study night and 1,469 women the second study night. Of those, 521 reported being interviewed and receiving a pen or a calendar the previous week. That gives an estimate of the sex work population of Bulawayo of  $(1,381 \times 1,469) / 521$ , or 3,894. This is far lower than the one-night count of the women at all 56 bars, which came in at 6,973, and the difference between the two totals is statistically significant. It was, however, higher than the 2,864 women counted in a single night at the 15 bars selected for the study.

## Conclusion

Overall, then, the capture-recapture method performed rather poorly in this situation. It involved a total of over 2,800 interviews in the course of two evenings, while the straight one-night count of all women at bars did not involve approaching women at all. Unfortunately, it is likely that without a bona fide way to link records from caught and recaptured individuals, almost any two-sample study will be plagued with unsolvable problems in interpretation. There are no clear advantages to a two-sample capture-recapture approach in settings where enumeration is feasible and linking records is not.

Estimating the size of at-risk populations such as sex workers remains critical for designing and evaluating targeted AIDS-prevention programs. In settings where straightforward enumeration is not possible, because the population is not visible, the accuracy of capture-recapture estimates could be improved in several ways. For example, improvements could be made in the acceptability of the unique identifier used to link responses from the same individual. It might be more acceptable for a respondent to create a secret password that she could remember and report if interviewed a second time. The capture-recapture estimate could also be improved by interviewing a sample of individuals on a third night. The proportion interviewed three times compared to the proportion interviewed two times provide an estimate of the extent to which catchability differed each night and can be used to adjust the original estimate. Finally, another approach that might improve the estimate would be to carefully estimate the size of the population at a subset of bars in a certain geographic area using a capture-recapture or other method and then inflate this estimate according to the total number of bars.

## Notes

[1] The full study is reported in “The Use of Capture-Recapture Methods to Improve Evaluation of AIDS Prevention Program,” unpublished dissertation of Sharon Weir, Department of Epidemiology, University of North Carolina at Chapel Hill.

## HIV prevalence trends among young antenatal women are a good indicator of recent trends in the AIDS epidemic

*Basia Zaba, Ties Boerma and Richard White*

- ✓ HIV prevalence trends among young antenatal women are good indicators of HIV incidence trends in most circumstances.
- ✓ In general, a wide age interval should be used (15-24) rather than five-year age groups (15-19).
- ✓ Monitoring HIV trends in antenatal clinics by parity 0 and 1 further enhances the ability of antenatal data to describe true trends.
- ✓ Simulations suggest that swings in the HIV prevalence curve among antenatal women over time may exaggerate trends in HIV incidence.

### *Antenatal-clinic-based surveillance*

Reliable data on HIV incidence (new cases) are essential for monitoring the spread of HIV. Unfortunately, incidence data are difficult and costly to collect. In many countries, HIV prevalence among women attending antenatal clinics (ANC) will continue to be the main source for monitoring the epidemic and assessment of the impact of interventions to reduce transmission.

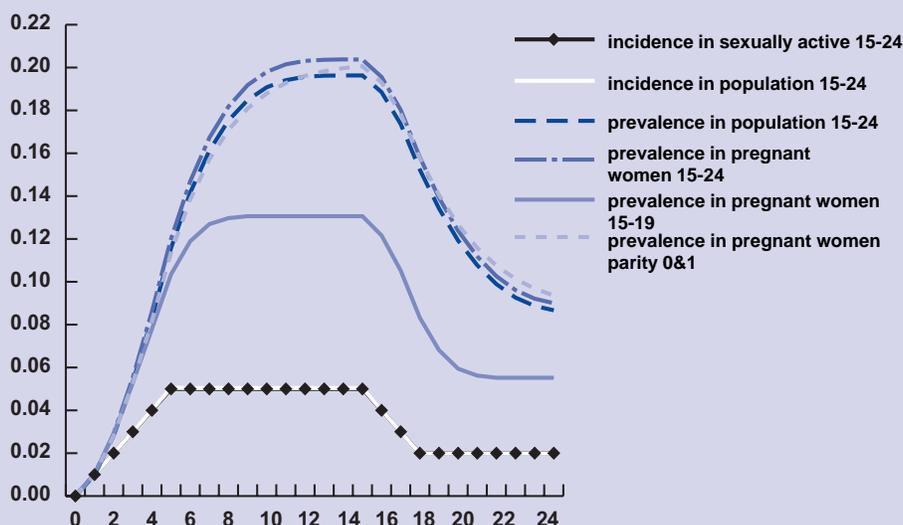
The focus of ANC-based surveillance should be on young women. In two national success stories in the battle against AIDS, Uganda and Thailand, HIV prevalence declined first in younger, antenatal women. If such changes occur, careful consideration needs to be given to a number of biases before drawing conclusions about trends in the general female adult population (see Box 1).

### *Indicators of prevalence among young women*

The preferred age group for monitoring HIV prevalence among antenatal women is 15-24. This age group is large, so that sufficient numbers of antenatal women can be obtained easily. HIV prevalence at 15-24 is also a good indicator of prevalence among all ANC women. Monitoring among ANC women 15-19 years could pick up changes among the youngest age group, who are often targeted in interventions. The disadvantages are sample size requirements and higher sensitivity to biases.

A third indicator is HIV prevalence at first and second pregnancy (here called parity 0-1). Most antenatal clinics routinely collect data on the rank order of the pregnancy, but such data are rarely reported in HIV sentinel surveillance. In populations with low contraceptive use, the birth order (parity) of a young pregnant woman is a more precise measure of sexual exposure than her age, especially if there is wide variation in age at first sex, or if initial sexual contacts are sporadic and infrequent.

## Scenario 1. HIV incidence decline in sexually active due to lower transmission risk



### Simulating time trends in prevalence

How good are the ANC-based HIV prevalence indicators in picking up changes in HIV incidence in the adolescent female population? What is the best indicator to use? A projection model can assess how well trends in HIV prevalence among young antenatal women reflect HIV incidence trends in the young women general population if changes occur in the age at first sex and in the risk of HIV transmission. The model's projections focus on a 25-year period, and it is assumed that incidence among the sexually active rises linearly from year zero and flattens out at 5% per year in year 5. Incidence is allowed to fall after a plateau of at least five years in the three scenarios. All changes are grossly exaggerated and simplified to illustrate more clearly the effects on the prevalence indicators. All scenarios show prevalence trends among pregnant women 15-19 and 15-24, among pregnant women of parity 0-1, and among all women 15-24.

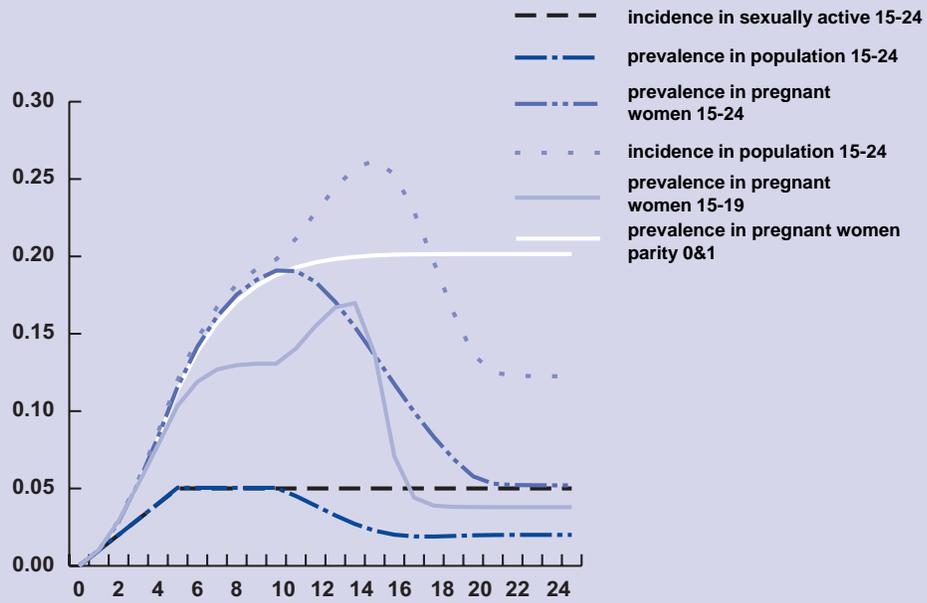
### Scenario 1: HIV incidence decline in sexually active due to lower transmission risk

Trends in the population prevalence measure for ages 15-24 are echoed closely by trends in prevalence among pregnant women aged 15-24, and by trends for those experiencing first and second births. Trends for 15-19-year-olds follow a broadly similar pattern, but at a lower overall level. All the measures respond immediately to the decline in incidence rates among the sexually active, which starts in year 15. However, prevalence levels off 3-4 years after incidence increases or the decline levels off.

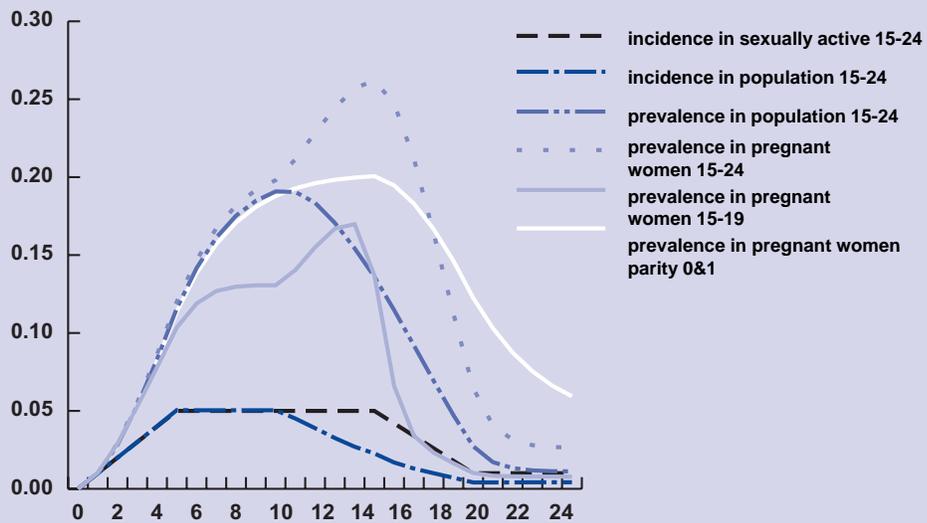
### Scenario 2: Increase in age at first sex

Incidence among the sexually active remains constant at 5% per year for the rest of the projection period, but the median age at first sex rises rapidly between calendar years 10 and 13. The decline in incidence that takes place after year 10 is due to a rise in the age at first sex, eventually producing a fall in incidence in the age group 15-24 from 5% to 2%, even though the risk to the sexually active does not change. Although the change in age pattern of sexual debut takes only 3

### Scenario 2. Increase in age at first sex



### Scenario 3. Scenario 1 + Scenario 2



years to accomplish (as with the fall in HIV risk in Scenario 1), it takes about 7 years for incidence to fall from 5% to 2%.

### **Scenario 3: Scenario 1 + Scenario 2**

The scenario combining a fall in incidence among the sexually active (as in the Scenario 1) with a rise in age at first sex (Scenario 2), shows that prevalence trends in the parity-based data give a truer representation of incidence trends than the age-based data. Changes in prevalence among pregnant women classified by parity consistently lag behind population-based changes in incidence in the 15-24 age group. Trends in the age-based pregnant prevalence measures have an erratic relationship to population-based incidence trends, just as in the previous simulation.

### **Conclusion**

The simulations show that for ANC-based HIV prevalence, estimates are useful as predictors of incidence, if the age group used is wide (15-24 rather than 15-19) and, that it is useful to collect parity-based information to complement the age-based data, as the two data types are subject to slightly different biases. Parity-based indicators are better at reflecting the dynamics of infection in the sexually active population, but age-based measures may be better at portraying stable incidence levels in young women as a whole.

Prevalence measures tend to lag behind changes in incidence, but age-based measures in pregnant women may also be subject to rapid fluctuations, if there are significant changes in age at first sex due to changes in the composition of the age group by time since first sex. These fluctuations may give the impression that incidence is rising when it is, in fact, already

falling, or that a rapid decline is occurring, when the pace of the incidence decline is quite moderate. Age-classified antenatal prevalence data may exaggerate the height of the peak incidence and prevalence levels in the community and the pace at which change takes place. However, such biases are transitory and the stable prevalence level eventually attained in pregnant women aged 15-24 should be a reasonable guide to the stable incidence level in this age group in the general population. Comparisons with trends in prevalence among women expecting their first and second births could identify spurious transient trends in age-based measures, as parity-based measures should be less affected by changes in age at first sex.

### **Source**

Basia Zaba, Ties Boerma and Richard White. Monitoring the AIDS epidemic using HIV prevalence data among young women attending antenatal clinics: prospects and problems. *AIDS* 2000, 14:1633-45.

## Monitoring the response to the AIDS epidemic using print media

Maria Khan and Sara Holtz

- ✓ **Based on an analysis of 3,154 newspaper titles on AIDS from Kenya, Tanzania, and Zimbabwe, analysis of newspaper articles appears to be a useful, relatively inexpensive and easily accessible source of information about political and social response to the AIDS epidemic. However, this method may not be appropriate for the detailed monitoring of trends over time in all topics. Realistically, newsprint analysis simply provides a “snapshot” of social and political responses to AIDS.**
- ✓ **Analysis of the title and the first paragraph, rather than the entire article or the title alone, may be the most thorough and feasible method of extracting indicators from newspaper articles.**
- ✓ **This analysis of newspaper titles indicates an increase in positive response to the AIDS epidemic in Kenya, Tanzania and Zimbabwe during the nineties, including increased emphasis on AIDS awareness and action initiatives. While encouragement of behavior change and reduction in stigma of AIDS steadily increased during the nineties in Kenya and Tanzania, similar improvement was not observed in Zimbabwe.**

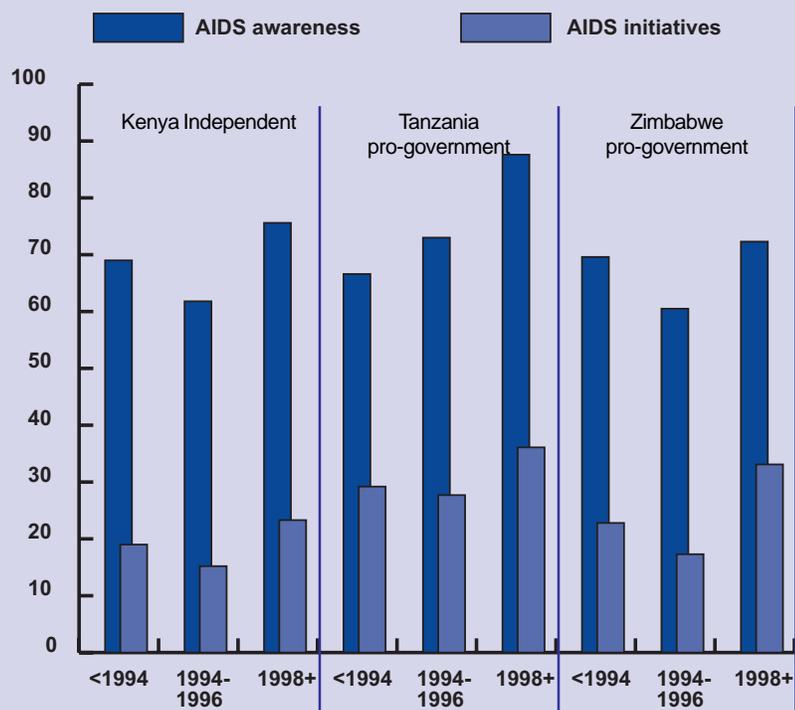
A review of articles appearing in the major newspapers in a country is likely to provide an indication of the importance placed on issues and events discussed in those articles and prevalent attitudes toward them. In order to determine the viability of this method for monitoring response to the AIDS epidemic and to assess the political and social responses to the AIDS epidemic in Kenya, Tanzania, and Zimbabwe, AIDS-related articles that were collected from resource centers in Kenya, Tanzania and Zimbabwe were analyzed. [1] All three countries have experienced generalized AIDS epidemics for more than a decade. The number of newspaper sources from which articles were chosen varied between the three countries. In Kenya, most articles were collected from the pro-government paper, *Kenya Times* and from the independent paper, *Daily Nation*. In Tanzania, the pro-government papers included *Daily News* and *Sunday News*, while *The Guardian* was the most important source of articles from the independent papers. In Zimbabwe, *The Herald* was the most important pro-government source while the *Daily Gazette* was the

most important independent source. A total of 3,154 newspaper article titles were analyzed: 1,150 from Zimbabwe, 1,056 from Tanzania and 948 from Kenya. The sample included a total of 1,095 titles prior to 1994, 1,244 titles from the mid-1990s and 815 titles from the late 1990s. Results of this analysis should be interpreted with the knowledge that the decade-long process of newspaper collection was not monitored.

### *No clear trend in the number of AIDS-related articles over time*

The number of AIDS-related articles published per month varied considerably between newspapers, with no clear trend observed. The Kenya pro-government newspaper and the Tanzania independent newspaper showed an increase in 1998-99 compared with earlier periods, although the number of articles in the Tanzania independent newspapers was small. Others showed a decline in the late 1990s.

**Figure 1. AIDS awareness and AIDS initiatives  
(% of all articles)**



about events to raise awareness were coded in this category, “*Tennis great Arthur Ashe dies from AIDS.*”

### Coverage of AIDS initiatives greatest in the late 1990s

Reports of AIDS action initiatives to address the epidemic was the second most frequently reported topic, with especially strong coverage observed in both Tanzanian government and independent papers (30% of articles and 29% of articles, respectively) and in Zimbabwean independent papers (28% of articles). Reporting on action initiatives was greatest in the late 1990s (see Figure 1). Titles coded as “AIDS initiative” included reports of action by the government, groups or individuals, such as, “*WHO unveils new AIDS strategy,*” and, “*Farmers join in the battle against AIDS.*” Titles coded in this category also called for involvement in AIDS initiatives, such as, “*National policy on HIV/AIDS needed*” or “*Let’s curb AIDS spread in Kisumu.*”

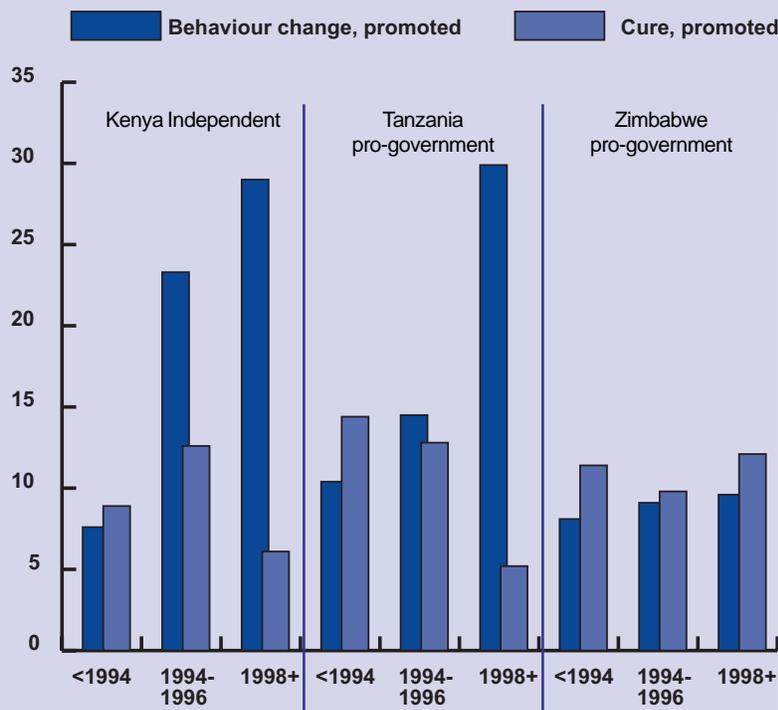
### Emphasis on a cure versus behavior change varied by country

### Reporting on AIDS awareness greatest in the late 1990s

Promotion of AIDS awareness was the most frequently reported AIDS-related topic for each country (66% to 79% of articles promoted AIDS awareness). The number of articles on this topic was greatest in the late 1990s, following a decline in such reporting in Kenya and Zimbabwe during the mid-1990s (see Figure 1). AIDS-awareness coverage included titles that promote knowledge about the existence and extent of the epidemic, such as, “*Mandela urges South Africans to end silence over AIDS,*” “*Public lacks constant information on AIDS*” and “*AIDS orphans now 100,000.*” Titles coded as “AIDS awareness” also discussed transmission risks, “*People with wounds must be cautious in handling body fluids*” and encouraged knowledge about HIV status, “*Voluntary counseling and testing promotes HIV prevention.*” Awareness in articles also could counter myths about transmission, “*Mosquitoes ‘don’t transmit Aids,’*” and challenge stigmatization of people with AIDS, “*AIDS patients up against being discharged.*” Finally, titles reporting celebrities with AIDS or

A focus of newspaper coverage on issues related to a cure for AIDS rather than behavior change may indicate a lack of emphasis by governmental and non-governmental organizations on behavior change, or prevention. In the late 1990s, articles in Tanzania and Kenya tended to promote behavior change rather than a cure, while a cure was more likely to be emphasized than behavior change in Zimbabwe (see Figure 2). In Tanzania, though reporting on a possible cure was quite common in the early 1990s, a steady decline is observed during the most recent period. A cure was a frequently reported issue in the mid-1990s in Kenya because a local anti-retroviral drug, Pearl Omega, raised expectations of one, while reporting on this topic sharply declined in the late nineties. In Zimbabwe, a cure remained a frequently reported topic in the late 1990s, with 15% of titles during all the three time periods related to one. Titles thought to encourage a cure reported advances in both biomedical treatments, “*Govt says Obel’s AIDS drug works,*” as well as traditional cures, “*Human urine cure for AIDS?*” Some titles emphasized the primary importance of cure, “*AIDS: Focus is on finding cure.*”

Figure 2. Promotion of cure versus promotion of behavior change (% of all articles)



Articles on behavioral change steadily increased in Kenya and Tanzania to a high of about 30% of articles in the late 1990s, while the number of articles on behavioral change in Zimbabwe remained at 10% through the three time periods. The independent papers in both Kenya and Tanzania were much more likely to report on behavior change (26% of articles and 25% of articles, respectively) than the government papers (16% of articles in both countries). Articles encouraged behavior change by advising, “*Strive to keep off casual sex,*” and by reporting safe sexual behavior, “*Villagers rush for condoms.*” Attention to prevention and education was also considered promotion of behavioral change, “*Focus on AIDS prevention, Africa told,*” and “*Child to child project imparts children with health education.*”

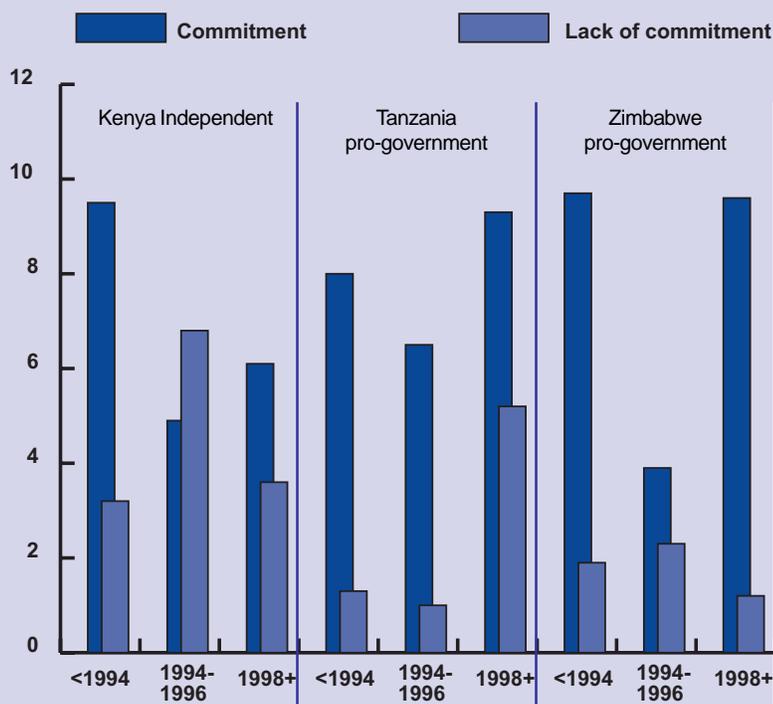
Articles on condom use, a related aspect of behavior change, remained low based on analysis of titles, with independent presses in Kenya and Tanzania slightly more likely to contain titles about condom use than the government presses in these countries. No clear trends over time were detected.

## Government commitment or positive response to the AIDS epidemic was difficult to Measure

Although reported in Figure 3, government commitment was particularly difficult to measure through newspaper title analysis because initiatives discussed in the article were not consistently reflected in the title. Despite low percentages of titles clearly indicating government commitment, certain similarities and differences between countries and news type could be detected. In general, reporting of positive government response to the epidemic was more common (7% of articles) than was criticism of the government (3% of articles) in both government and independent papers in each country. As would be expected, government papers in each of the three countries contained more articles reporting positive government response to AIDS. Trends over time are not clear, though a slightly greater percentage of articles reporting positive government response was observed in the early period, prior to 1994, and in the late 1990s than was reported in the mid-1990s (Figure 3).

A title was considered to describe a positive response by the government if it reported on policy initiated for prevention programs, AIDS awareness and/or protection of AIDS patients, such as, “*New laws protect HIV positive employees from discrimination,*” and “*Senate passes Aids testing Bill.*” Promotion of AIDS awareness and reports of changes in sexual behavior by government officials was also considered a positive government response, “*AIDS danger in Tanzania real - government official,*” “*Minister decries casual sex,*” and “*Prime Minister to attend AIDS rally in Arusha.*” Criticism of the government included reports that the government had failed to implement appropriate policy, “*Gweru fails to cope with TB patients,*” “*Call to amend law to curb spread of Aids,*” “*Government leaders should act on AIDS charlatans,*” and “*UNICEF blames Tanzania’s health care.*” Reports of statements by governmental officials that negatively respond to prevention of AIDS or care for people with AIDS were also considered in this category, “*No future care for AIDS victims, says Angatia.*”

**Figure 3. Government commitment versus lack of government commitment (% of all articles)**



a harbor of AIDS,” “Discussions on the problems of women,” and “Educate a woman & you educate a nation.” People with AIDS were both stigmatized and sensationalized, described as “victims,” “sufferers,” “carriers” who are “contaminated,” “infected,” “contagious,” “suspect.” Criminalization by the media was also observed, “Aids: confine them.” Titles can also stigmatize certain groups at risk, implying they are the cause of the epidemic. Articles targeted groups such as “women,” “homosexuals,” “the poor,” “sex workers,” “truck drivers,” “migrant workers,” “prisoners,” “street children,” “foreigners,” “tourists,” “military personnel,” and “fishermen/sailors.”

*Detailed analysis of titles and first paragraph likely provides the best combination of feasibility and data quality*

Advantages of simply analyzing the title are multiple. Titles are short and can easily be copied. Compared with analysis based on the entire article, a fairly objective and documented coding system can be developed, while multiple coders can also be used to enhance objectivity. In addition, discourse analysis can more easily be performed on the title than on the entire article, owing to its short length. A title, however, may not adequately cover the content of the article.

*Attitudes toward people with AIDS improved over time*

Although media coverage included articles stigmatizing AIDS, a substantial increase in the percentage of articles challenging stigmatization was observed in the mid- and late 1990s. Figure 4 shows a dramatic trend toward less stigmatization in the Kenya independent paper and Tanzania government papers. A much smaller increase was observed in the Zimbabwean government paper. Titles were considered to challenge stigma if they suggested a change in behavior or attitudes, reported on stigmatization or described a movement to fight stigma. Some titles overtly reported that, “AIDS victims should not be stigmatized,” and “It’s not just about one group but everyone is at risk and everyone is involved in prevention.” Other titles indirectly de-stigmatize by explaining circumstances underlying risk factors for the disease, “Economic disparities lead to teenage prostitution.”

Though stigmatization was observed in less than 10% of the articles in each of the countries, its presence remains striking. Stigmatizing articles included, “The needy street child is

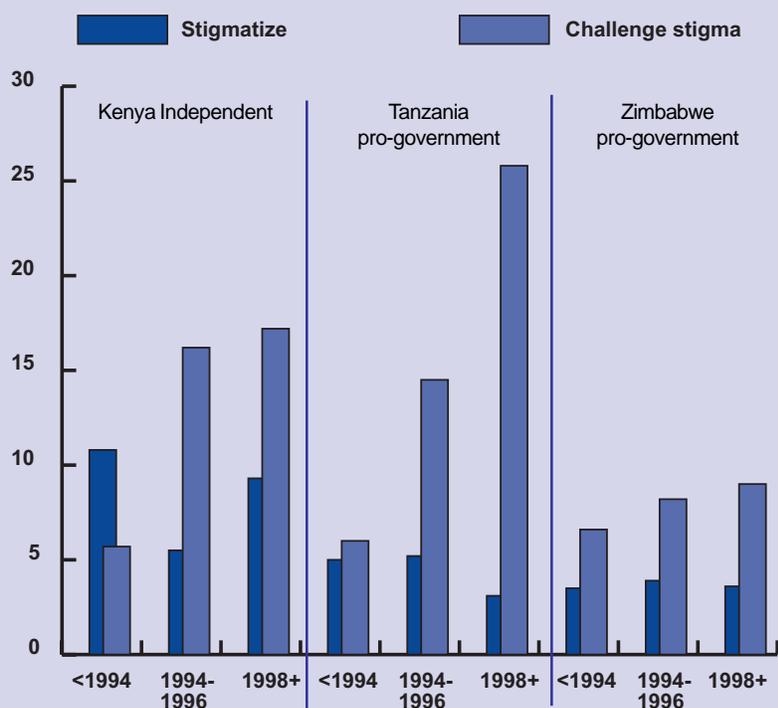
article, owing to its short length. A title, however, may not adequately cover the content of the article.

To assess the validity of the title as an indicator of response to the AIDS epidemic, coding results based on the title were compared with results based on the title plus the first paragraph and results based on review of the full-length article. A subset of article titles (n=184) was extracted from the larger group of 3,154 titles and linked to full-length articles. First, the titles and the corresponding first paragraphs were read and coded without reviewing the previous coding of the titles. In a second phase of analysis, the entire article was read and additional codes were identified and recorded.

*An effective coding device for newsprint analysis is the title and first paragraph*

Analysis of the 184 articles indicates that a total of 511 of the AIDS-related codes were identified, based on the title plus the first paragraph, while only 280 codes were identified when coding was based only on the title. Comparing the coding for the title with coding for the title and the first paragraph indi-

Figure 4. Stigma of AIDS versus challenge to stigma (% of all articles)



cates that the title alone “misses” relevant codes and articles that can be identified when the text of the article is also analyzed. The most common topics to be “missed” when the title alone is analyzed involves AIDS initiatives and government response to AIDS. While the title gave less information than the first paragraph, the distribution of the major codings did not dramatically change between the two methodologies, and the additional information from the first paragraph rarely contradicted the coding based on the title.

### Coding based on the entire article is inefficient

Although more information is obtained by reading the entire article, coding becomes more difficult and time consuming. A newspaper article often presents opposing views, so coding for the entire text of the article often included contradictory codes. Coding based solely on analysis of the title and first paragraph is a more efficient analytical tool, because the article’s primary point of view is generally expressed in the first lines of the article.

## Conclusion

Complications at both the data collection and analysis phases could result in inconclusive findings in analysis of print media. The use of existing databases for retrospective analyses – as was done here – always brings the risk of incomplete data and makes it difficult to judge the biases after the fact. During analysis, articles may be missed or inaccurately coded depending upon the method used. For example, coding the full article is cumbersome and can yield contradictory results while remaining time consuming. While using titles only is a rapid alternative to coding the entire article, this method may not be suitable for all topics.

Detailed analysis of an article’s title and first paragraph probably provides the best combination of feasibility and data quality. Using an efficient coding methodology such as this could provide a useful “snapshot” of a country’s public attitude and response to the AIDS epidemic, including AIDS awareness and action initiatives, government commitment, emphasis of response on prevention or cure, stigmatization and challenges to stigmatization.

## Notes

[1] The AIDS NGO Consortium (KANCO) in Nairobi, Kenya; National AIDS Control Programme (NACP) in Dar es Salaam, Tanzania; and, Southern African AIDS Information Dissemination Service (SAfAIDS) in Harare, Zimbabwe collect HIV/AIDS-related newspaper clippings from daily and weekly newspapers.

## References

Khan M. and Holtz S. Monitoring the Response to the AIDS Epidemic Using Print Media in Kenya, Tanzania and Zimbabwe. MEASURE *Evaluation* Special Publication, forthcoming.