

high proportion of MSM reported to the HIV/AIDS case surveillance. Though one survey of JEPA based on 165 semen specimens extracted from trash box wastes collected at bathhouses in Tokyo revealed around 20% of HIV positivity in 1996, this study discontinued because of controversy with gay NGOs.

#### ***Results of sentinel serosurveillance***

Overall prevalence of the HIV antibody among *donated blood Samples* (not blood donors) has been steadily increasing now reaching 0.9 per 100,000. This rate is equivalent with the levels of many European countries, which is however 10 times greater than European countries when expressed relative to the extent of the epidemic. This result indicates that blood donation tends to be used as an opportunity for HIV testing disproportionately more in Japan than western European countries. The HIV antibody had remained negative among *pregnant women* until 1995. However several positives have been detected since 1996 giving a prevalence around 5-10 per 100,000. Likewise, though seroprevalence of *STD patients* had been zero until 1996, several positives have also been detected in 1997 giving a prevalence around 230 per 100,000. Seroprevalence among *voluntary HIV testers* at public health centers continues to increase, reaching 230 per 100,000 in 1997, a 5-fold increase from the rate in 1992. This increase was a product of a progressive reduction in the number of testers and the reciprocal increase in the number of HIV-positives. HIV seroprevalence among *foreign CSW* attending STD clinics, mostly Southeast Asian origin, was fairly stable varying 1-3% since 1992. HIV seroprevalence of "soapland" *Japanese CSW* has remained at zero level. Also HIV seroprevalence among *IDUs* has been below 0.1% among those arrested and zero among IDU inpatients.

#### ***Dissemination and resultant actions***

All this data is published in an annual report of JEPA and distributed to all public health centers, public laboratories, medical libraries, HIV-related NGOs and made available to anyone upon request. About 1500 are printed every year. Annual statistics of screened bloods are released to the press every year in January. As mentioned earlier policy-making mechanism has not been well established to translate epidemiological findings into action.

#### ***Problems and future perspectives***

Except for the routine checking of donated blood all serosurvey research is financed on a 3-year basis by the Ministry of Health and Welfare. This makes long-term or large-scale planning difficult. Since sampling is biased or unstable depending on the population sampled, a more systematic sampling strategy should be planned and

implemented, especially for pregnant women, STD patients and Japanese CSW. And the need for the development of serological monitoring of MSM is desperately urgent.

#### (4) MOLECULAR SURVEILLANCE OF HIV-1

Molecular typing of HIV-1 using PCR and/or ELISA has been conducted by JEPA for the sample of cases of known transmission category since 1992 as well as for HIV positive donated bloods since 1996. This survey revealed that **subtype B** of HIV-1 continued to be dominant in Japanese men infected homosexually, whereas it has shifted to **subtype E** in those infected heterosexually since 1994. Only subtype E has been detected among foreign CSW of Southeast Asian origin since 1992. HIV-1 subtype of positive donated bloods was mostly B. These findings suggested that the HIV-1 substrain now spreading is the one more efficiently transmissible through heterosexual contact, clearly affected by the epidemic in other Asian countries and that HIV positives detected through blood donation are likely to be those infected through homosexual contact.

#### (5) BEHAVIORAL SURVEILLANCE OR SURVEYS

##### *General population*

No behavior surveillance program nor systematic collection of behavioral data has been introduced in Japan. A nationwide survey for the general population was conducted once by JEPA in 1994 using the mailing method, the result of this however was very poor on account of less than 20% response. The second nationwide survey (*The "Sex in Japan" Project*) with 5,000 probability samples using an anonymous self-administered questionnaire is now in the final phase of preparation after 2 pilot studies with respective 200 probability samples. A structured questionnaire (**MKBQ**, **M**asuring **K**nowledge and **B**ehavior **Q**uestionnaire) was developed to enable comparison with the major surveys conducted in other developed countries. MKBQ contains around 150 questions and takes 20-25 min to complete. An outline of MKBQ is attached. Response rates were around 70% in both pilot studies and they showed that although proportion of the people having more than 5 partners in the preceding year is similar, the frequency of paid sex is much higher, the frequency of sex is much lower in Japanese men compared to other developed countries. This type of survey will provide good indicators as to the effect of control measures taken if repeated at appropriate intervals.

##### *Populations subgroups*

JEPIA has launched a *Behavior Mapping Project* in 1998. This project, using the standard questionnaire (MKBQ) with minor modifications to suit the targeted

subgroups, aims to map variation in sexual behavior across population subgroups comparing the results with those of the *The "Sex in Japan" Project*. Intended subgroups include STD patients, university students, taxi drivers, construction workers, truck drivers, sailors etc. Pilot surveys have already been started among STD patients and university students.

Before this project began behavioral surveys on IDU inpatients and MSM were conducted. IDU inpatients have been consecutively sampled at drug treatment hospitals since 1995 and it has shown that needle-sharing practices are alarmingly common, about 50% reported sharing needle/syringes during the preceding year. HCV seroprevalence was extremely high (46.5% in 1997) and frequent unprotected sexual contacts with CSW was also noted. Behavior surveys for MSM has become possible since 1997 with close collaboration with gay NGOs. Convenient samples have been collected so far through those participating in parties or events and through the Internet. These studies showed that knowledge on STD is limited and unprotected receptive anal intercourse is still common. Intervention trials are now in preparation in Tokyo as well as in Osaka in cooperation with the Center for AIDS Prevention Studies (CAPS), UCSF, using venue-based samples. Questionnaires for these surveys will soon be standardized to MKBQ.

#### ***Dissemination and actions which result***

All this data is published in an annual report of JEPIA and distributed nationwide as mentioned above.

#### ***Problems and future perspectives***

Though these studies outline the spectrum of sexual risk for HIV acquisition across the population subgroups thus helping the policy-makers to target preventive efforts, they are only financed on a research basis. Mechanism should be also developed to translate these findings into the policy-making processes.

### **3. HIV/AIDS PROGRAM EFFECTIVENESS MONITORED AND EVALUATED BY SURVEILLANCES AND SURVEYS**

National surveys conducted to evaluate the status of HIV/AIDS-related knowledge and attitudes were performed three times on 10,000 random samples from the general population, last in 1995 (response rate = 73%). It showed that people were very well informed on classic knowledge on the modes of transmission. However, the recent JEPA's nationwide survey on 2,000 random samples (response rate = 67%) revealed that there is a deep gap in the knowledge on appropriate timing for HIV-testing, HIV-STD interaction and STDs in general; only half of the respondents could provide a correct

answer to the question that "HIV infection can be diagnosed within 2-3 days of infection" and only 30% knew that "STDs enhance the susceptibility to HIV infection". It also revealed that only 65% of people are aware that free anonymous testing is available at local public health centers though it has been in practice since 1992. In addition, it has been noted in STD surveillance that the incidence of gonorrhea and chlamydia has been rapidly increasing during the last 5 years. Though all these facts together with the results of surveillance and surveys have clearly suggested the increasing potential for future outbreak or needs for further targeted campaigns, little effort has been done to shape the HIV/AIDS strategy accordingly rather it has been limited to reproducing commonplace pamphlets, posters and small events at central level and local levels.

#### 4. CONCLUSION

The spread of HIV has been so far limited in Japan. However surveillance or survey results indicate the gradual spread of HIV in our society and the increased potential of future outbreak. We need better monitoring of HIV/AIDS and related behaviors to properly interpret the trends, which is crucial to guide and evaluate prevention and care programs. We also need policy-making mechanism to effectively translate epidemiological evidence into action. Any prevention and care efforts should be based on epidemiological evidence.

## National survey of 'sexual attitude and sexual behavior' survey categories

### **【Basic structure of the questionnaire】**

(1)General questions

(2)knowledge of AIDS, risk recognition

(3)Sexual behavior

- Sex life during the past one year (1. spouse/ partner, 2. other than spouse/ partner, 3. those to whom money was paid or given for sex)
- Most recent act of sex
- Sex life to date
- First sexual experience

(4)Degree of sexual satisfaction, adult amusement, sexual preference

(5)Sexual morality

(6)Environment during adolescence

(7)Sexual dysfunction, abuse, sexually transmitted disease

(8)Countermeasures against AIDS from now

#### ●(1).General questions

- |  |   |
|--|---|
| • Gender                                       | • Your education                              |
| • Age  | • House                                       |
| • Health condition                             | • Number of years living in current residence |
| • Number of people living together in a family | • Marital status                              |
| • Brothers sisters                             | • First marriage, remarried                   |
| • Your occupation                              | • Occupation and age of spouse                |
| • Work late, on Sundays or holidays            | • Spouse's education                          |
| • Hours of work per week                       | • Living together with parents                |
| • Hours spent at home per day                  | • Married couple have their own room          |
| • Spending money per month                     | • Number of children                          |

#### ● (2).Regarding knowledge of AIDS, risk recognition

- |  |   |
|--|---|
| • General question about AIDS                    | • Risk of AIDS (with regard to oneself) |
| • Risk of AIDS (with regard to Japan nationwide) | • AIDS test                             |
|  | • Where tested                          |

● (3).Regarding sexual behavior

- What is sex to you (for woman)
- Ones experience to date ·Pregnancy
- Means of contraception ·Age when first pregnant
- Abortion

◎ Regarding ones sex life during the past year

- Change in sex life during the past year
- Reason for change
- Details of change
- Sexual experience during the past year, number of partners, simultaneously

(1) Regarding sex with "spouse/partner"

- Sex with "spouse/partner" ·Use of condom at the time
- Number of partners ·Oral sex
- What kind of person/s ·Use of condom at the time
- Age of "spouse/partner" ·Anal sex
- Nationality of "spouse/partner" ·Use of condom at the time
- Occupation of "spouse/partner" ·Frequency of sex
- Education of "spouse/partner" ·"Spouse/partner" having sex partner/s
- First sex with "spouse/partner"(when) other than oneself
- Vaginal sex

(2) Regarding sex with "other than spouse/partner"

- Sex with "other than spouse/partner" ·Use of condom at the time
- Number of partners ·Oral sex
- What kind of person/s ·Use of condom at the time
- gender of partner/s ·Anal sex
- Age of partner/s ·Use of condom at the time
- Nationality of partner/s ·Frequency of sex
- Occupation of partner/s ·Concern of AIDS during sex
- Education of partner/s ·Partner having sex partner/s other than
- First sex with partner (when) oneself
- Vaginal sex

**(3) Regarding sex with those to whom money was paid or given for sex**

- Sex with those to whom money was paid or given for sex
- Number of person/s
- Gender of person/s
- Nationality of person/s
- What kind of adult amusement facilities
- Went to adult amusement facilities alone
- Drinking at the time
- Vaginal sex
- Use of condom at the time
- Oral sex
- Use of condom at the time
- Anal sex
- Use of condom at the time
- Frequency of sex
- Concern of sexually transmitted diseases or AIDS during sex

**(4) Experience overseas**

- Overseas travel experience
- Destination/s
- Sex overseas
- Use of condom at the time

**© Regarding ones most recent act of sex**

- When you last had sex
- Who the partner was
- Where
- Vaginal sex
- Use of condom at the time
- Where ejaculated
- Oral sex
- Use of condom at the time
- Where ejaculated
- Anal sex
- Use of condom at the time
- Where ejaculated
- Where did you get the condom
- Why the condom was used
- Who put the condom on
- Trouble using the condom
- Was a condom available
- Why a condom was not used

**© Regarding entire sex life to date**

- Number of partners
- Sex of partners

**© Regarding ones first act of sex**

- (with the opposite gender)
- Ones age and partner's age
- First sex.. what you wanted
- Who the partner was
- Occupation of partner
- Use of condom at the time
- (with the same gender)
- Ones age and partner's age
- First sex.. what you wanted
- Who the partner was
- Occupation of partner
- Use of condom at the time

● (4).Regarding ones level of satisfaction with ones sex life, experience of adult amusement and sexual preference

- Satisfied with current sex life
- Adult amusement during the past year
- Masturbation during the past year
- Gender to which one felt attracted to sexually

● (5).Regarding sexual morality

- (personal opinion)
- Men having premarital sex
- Women having premarital sex
- Men having extramarital sex
- Women having extramarital sex
- Men with girlfriends having sex with others
- Women with boyfriends having sex with others
- Men having sex with other men
- Women having sex with other women
- Having sex by paying money
- Having sex by receiving money
- (perception of public opinion)
- Men having premarital sex
- Women having premarital sex
- Men having extramarital sex
- Women having extramarital sex
- Men with girlfriends having sex with others
- Women with boyfriends having sex with others
- Men having sex with other men
- Women having sex with other women
- Having sex by paying money
- Having sex by receiving money

● (6).Regarding your adolescence

- Environment
- Father's occupation
- Mother's occupation
- Age when first lived by oneself
- Age when one first worked
- Strictness at home regarding sex
- Was sex talked about at home
- Person you can consult regarding sex
- Source of information regarding sex

● (7)-1.Sexual dysfunction

- Problems with regard to sex (men) (women)

● (7)-2.Regarding sexual abuse

- Sexual abuse
- Sexual abuse detail



● (7)-3.Regarding sexually transmitted diseases (S.T.D.)

- Contracted an S.T.D. during the past year
- Name of disease
- Who the disease was contracted from

● (8).Future measures to prevent the spread of AIDS

- Current AIDS countermeasures
- Information regarding AIDS
- What information would you like regarding AIDS

# The current status and trends of HIV/AIDS epidemics in Japan

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The cumulative reported number of AIDS cases in Japan is 1,917 as of the end of 1998, excluding the cases infected through blood coagulant factor products [631 cases]. And the cumulative reported number of HIV-infected persons is 3,786 [Table 1]. As to exposure categories of HIV infection, receipt of blood coagulation factor products accounts for 23.1% of total reported cases, heterosexual contact 37.0%, men who has sex with men 18.7%, injecting drug use 0.5%, mother to child 0.5%, others 1.4%, and risk not reported or identified 18.8%. The structure of exposure category in reported AIDS is not so different except that receipt of blood coagulation factor products still accounts for 32.9% of total reported AIDS cases. Excluding the cases infected through blood coagulation factor products, nationality/sex distribution of HIV infected persons in Japan, was male of Japanese nationality 45.9%, female of Japanese nationality 8.9%, male of foreign nationality 13.9%, and female of foreign nationality 31.2%. And that of AIDS cases in Japan, was male of Japanese nationality 66.3%, female of Japanese nationality 5.7%, male of foreign nationality 19.9%, and female of foreign nationality 8.2%.

The annual reported number of HIV-infected persons in Japan had decreased after the peak in 1992, but now has a tendency to increase again, and that of AIDS cases is continuously increasing. While the annual reported numbers of HIV-infected persons of Japanese nationality is increasing, the number of female infection of foreign nationalities decreased slightly in 1998. The ratio of reported HIV-positive cases to reported AIDS cases was 1.59 in 1997 and 1.83 in 1998, has continued to decrease from 8.67 in 1992. The increase of reported number is mainly due to the increase of the cases infected through sexual contacts(heterosexual and MSM).

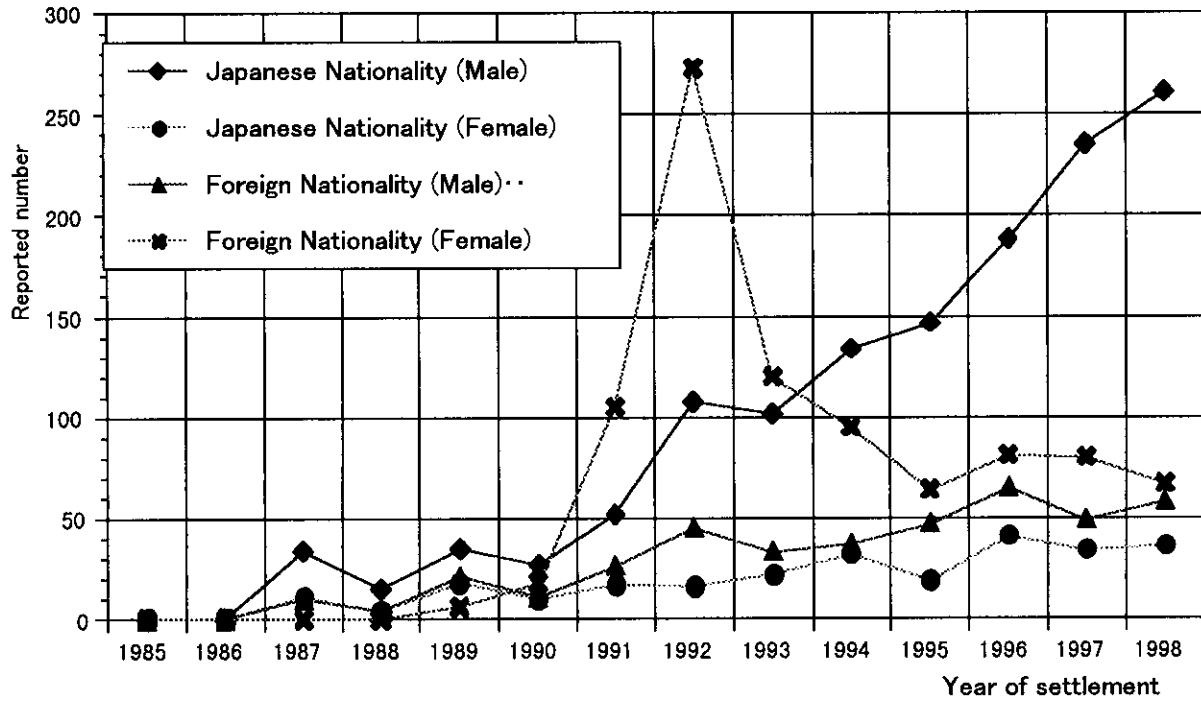
In 1998, 422 HIV-infected persons and 231 AIDS cases were reported. Compared with the numbers reported in 1997 (397 HIV-infected persons and 250 AIDS cases), the number of AIDS cases was smaller, but the number of HIV-infected persons was the largest ever reported in a year. By exposure category, sexual contact (heterosexual contact and men who have sex with men) accounted for the largest proportion of the reported cases (74.2% of HIV-infected persons and 64.9% of AIDS cases). Of HIV-infected persons reported in 1998, 61.8% were male of Japanese nationality, and of reported AIDS cases 68.3% were male of Japanese nationality. Most of the cases of Japanese nationality were reported to be infected in Japan. Compared with the report of the previous year, infections through sexual contacts, male cases of Japanese nationality have increased in HIV-infected persons.

The national average for annual incidence rate of adult donating blood at Japan Red Cross Blood Centers in 1998, was 0.897/ 100,000 donation, and is gradually increasing. Until the end of 1998, 5 cases of HIV infection which were reported to be infected through blood transfusion administrated in Japan after the introduction of the HIV-antibody screening test for donated blood in 1986. One case was confirmed as an infection through donated blood in window period. PCR as a screening test for donated blood will be adopted in the near future.

The monitoring of HIV prevalence among pregnant women, which provides an indication of general population, began in 1996, but the coverage of annual birth is about 13%. Six HIV positive cases in 1996 and 7 HIV positive cases in 1997(4.4/ 100,000 population) was detected.

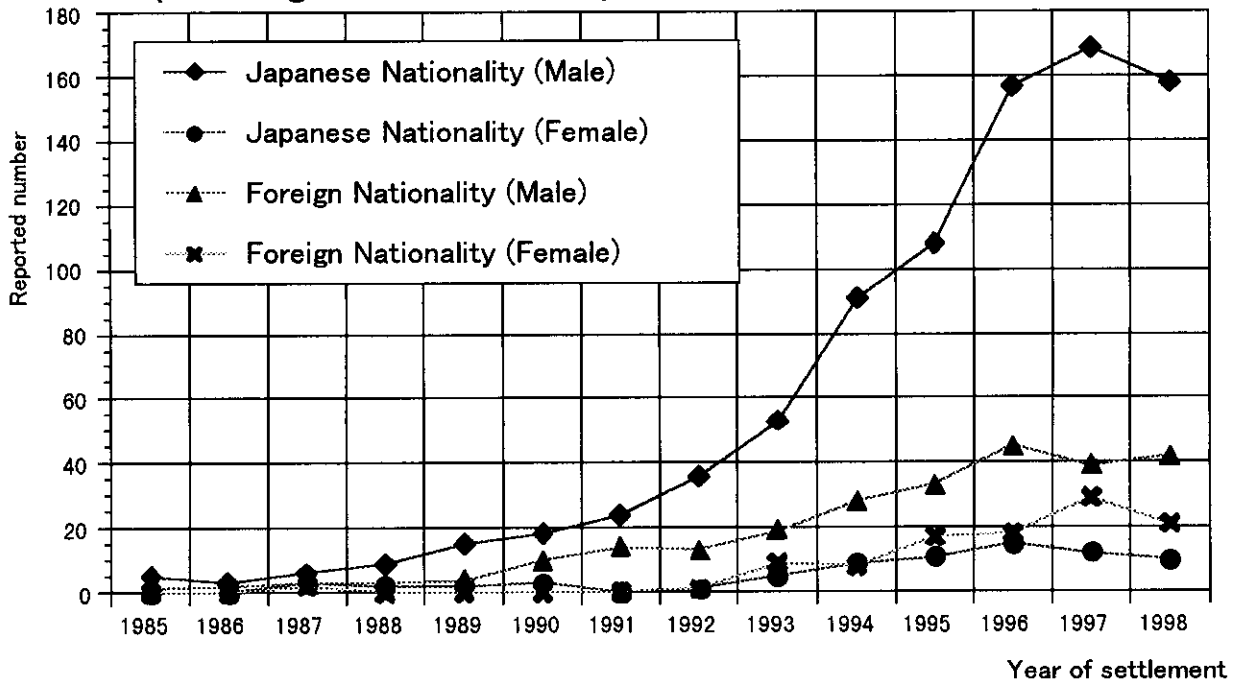
**Figure 1**

**The annual reported number of HIV infected persons in Japan by nationality and sex (excluding the cases infected through blood products)**

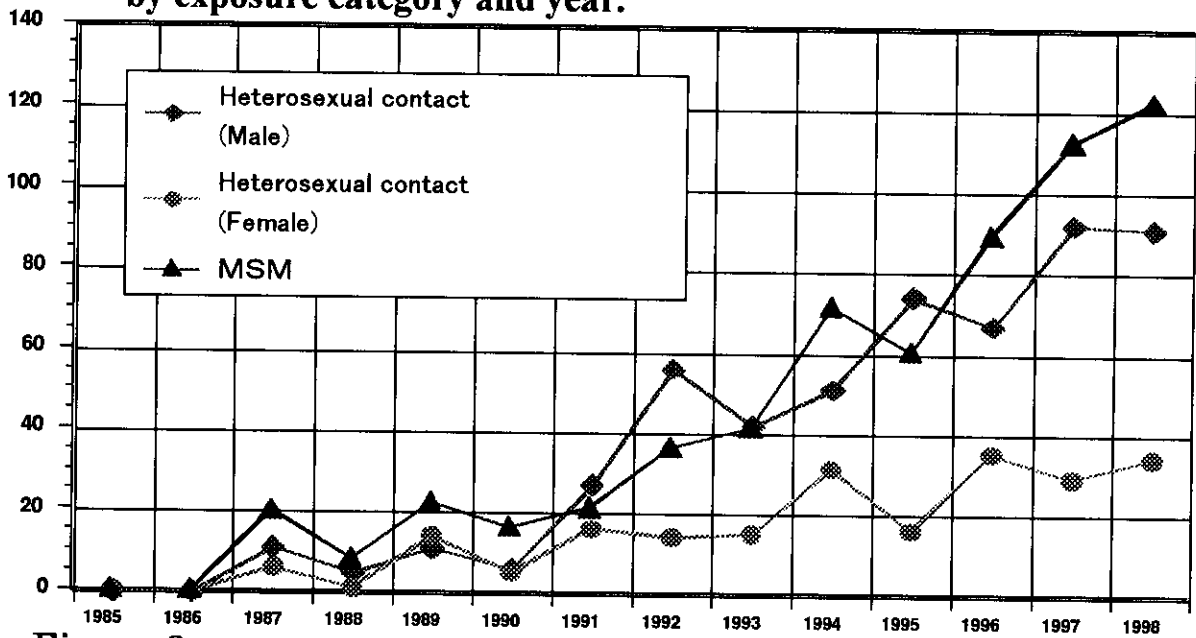


**Figure 2**

**The annual reported number of AIDS cases in Japan by nationality and sex (excluding the cases from blood products) (including the "transferred"(HIV→AIDS) cases)**

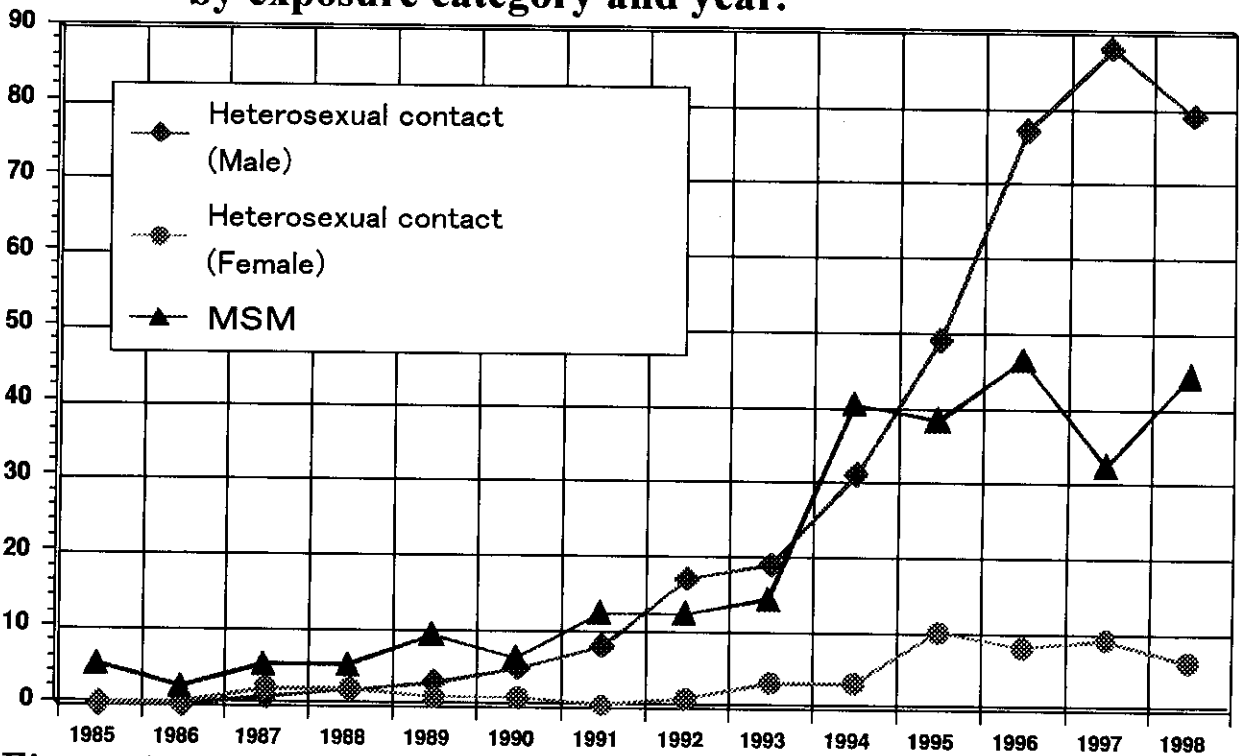


**HIV infected persons of Japanese nationality,  
by exposure category and year.**



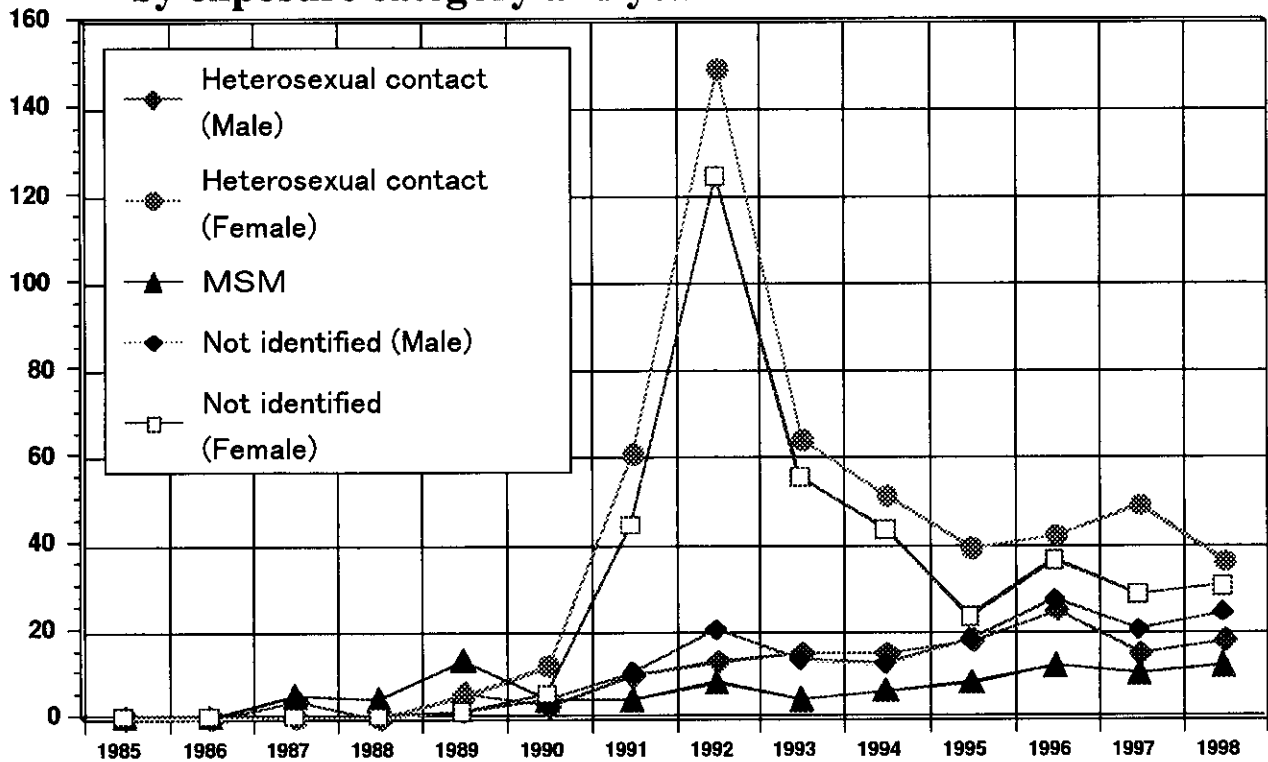
**Figure 3**

**AIDS cases of Japanese nationality,  
by exposure category and year.**



**Figure 4**

**Figure 5**  
**HIV infected persons of foreign nationality,**  
**by exposure category and year.**



**Figure 6**  
**AIDS cases of foreign nationality,**  
**by exposure category and year.**

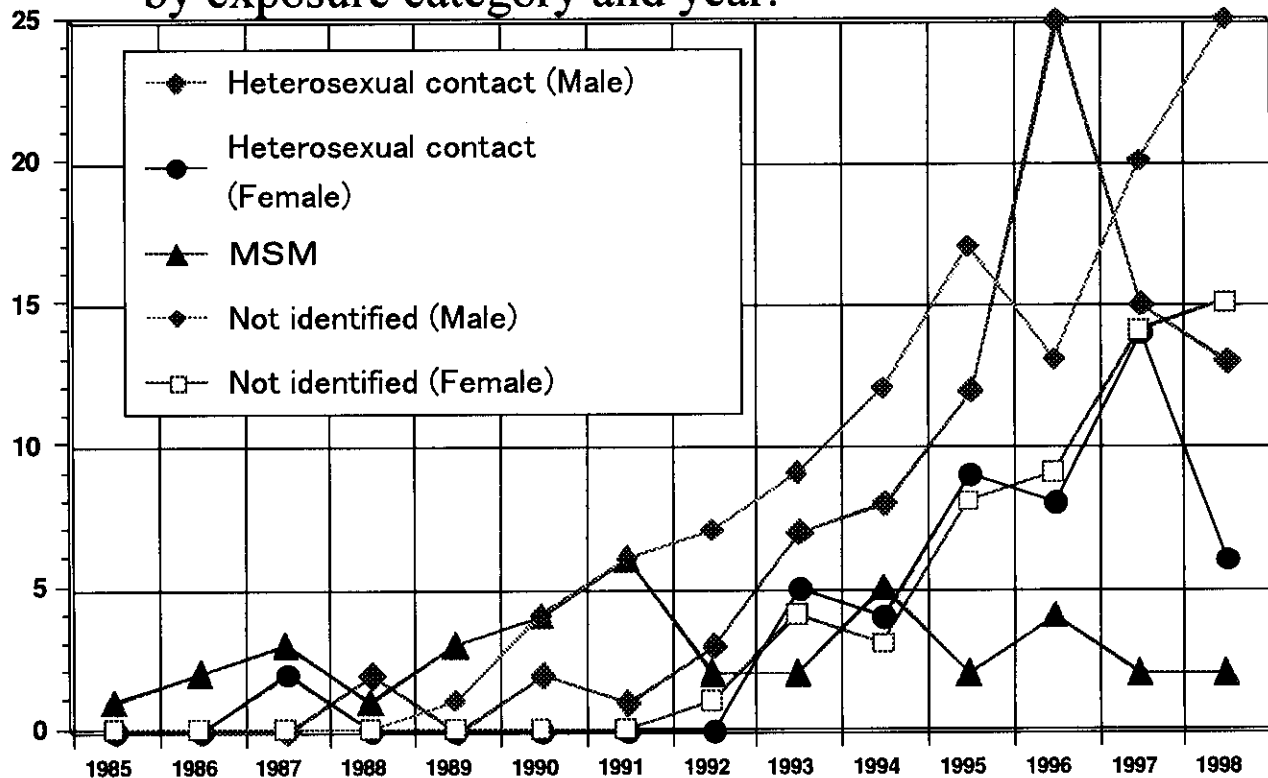


Figure 7

HIV Seroprevalence for blood donors in Japan, 1987-1998

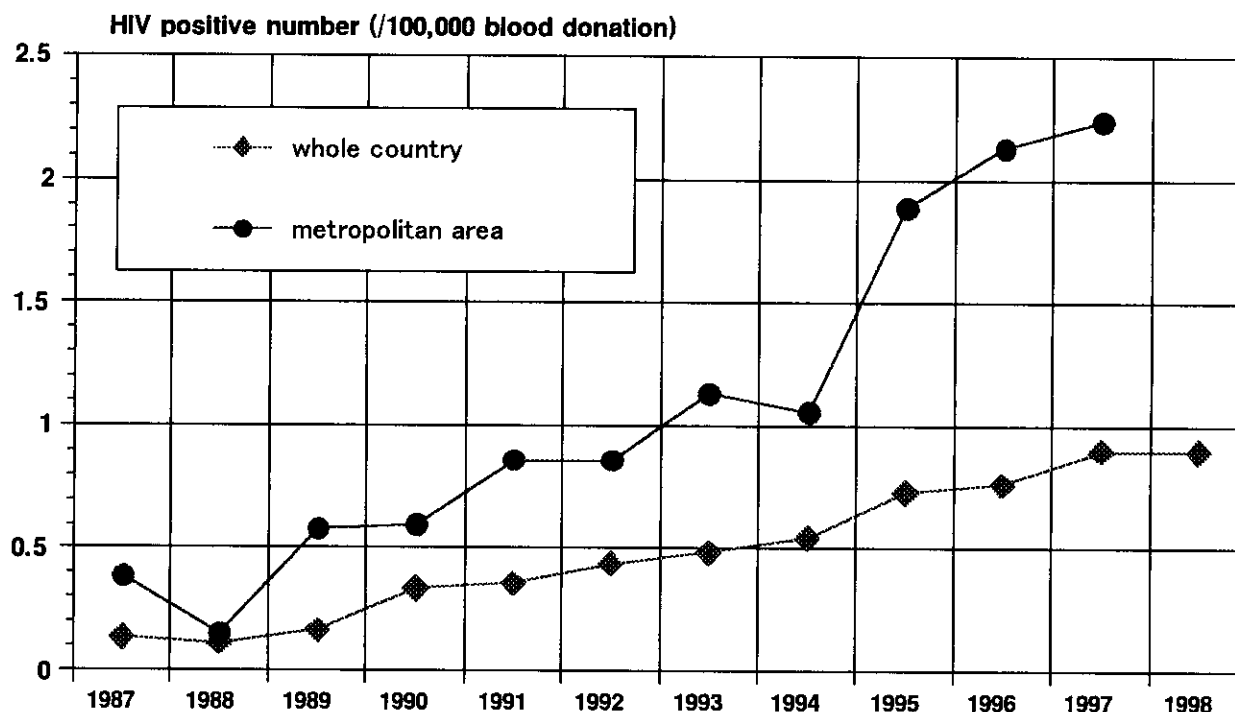


TABLE 1 HIV infections and AIDS cases by nationality, sex and exposure category, through 1998.

Diagnostic Classification	Exposure Category	Japanese nationality			Foreign nationality			Total		
		Male	Female	Total	Male	Female	Total	Male	Female	Total
<b>HIV</b>	<b>Heterosexual contact</b>	534	216	750	142	508	650	676	724	1400
	Men who have sex with men <sup>*1</sup>	618	0	618	90	0	90	708	0	708
	Injecting drug use	6	0	6	13	0	13	19	0	19
	Mother to child	7	5	12	2	6	8	9	11	20
	Other <sup>*2</sup>	17	18	35	10	6	16	27	24	51
	Risk not reported or identified	155	21	176	150	389	539	305	410	715
	<b>Subtotal</b>	<b>1337</b>	<b>260</b>	<b>1597</b>	<b>407</b>	<b>909</b>	<b>1316</b>	<b>1744</b>	<b>1169</b>	<b>2913</b>
	Receipt of blood coagulation factors <sup>*3</sup>	856	17	873	—	—	—	856	17	873
	<b>HIV Total</b>	<b>2193</b>	<b>277</b>	<b>2470</b>				<b>2600</b>	<b>1186</b>	<b>3786</b>
<b>AIDS</b>	<b>Heterosexual contact</b>	379	46	425	88	48	136	467	94	561
	Men who have sex with men <sup>*4</sup>	270	0	270	39	0	39	309	0	309
	Injecting drug use	4	0	4	9	0	9	13	0	13
	Mother to child	7	2	9	1	1	2	8	3	11
	Other <sup>*2</sup>	13	6	19	5	2	7	18	8	26
	Risk not reported or identified	179	19	198	114	54	168	293	73	366
	<b>Subtotal</b>	<b>852</b>	<b>73</b>	<b>925</b>	<b>256</b>	<b>105</b>	<b>361</b>	<b>1108</b>	<b>178</b>	<b>1286</b>
	Receipt of blood coagulation factors <sup>*3</sup>	624	7	631	—	—	—	624	7	631
	<b>AIDS Total</b> <sup>*5</sup>	<b>1476</b>	<b>80</b>	<b>1556</b>				<b>1732</b>	<b>185</b>	<b>1917</b>

\*1 41 bisexual male cases are included.

\*2 Includes cases from blood transfusion, tissue/organ transplant and cases with more than one possible mode of exposure to HIV.

\*3 The numbers are cumulative numbers of cases as of the end of October 1997, interim reported from the "Research Committee on Prevention of Developing Illness and Therapy for HIV infected Patients"

\*4 25 bisexual male cases are included.

\*5 Includes reported cumulative 493 death cases from the "Research Committee on Prevention of Developing Illness and Therapy for HIV infected Patients" and cumulative 596 death cases of other exposure categories.

## **Behavioral Surveillance: Current Perspectives and Its Role in Catalyzing Action**

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### *Introduction – Behavioral Data in Surveillance Systems*

General agreement has been reached that behavioral data are a valuable adjunct to traditional HIV and STD serological prevalence and incidence data. In the second generation surveillance systems currently being advocated by UNAIDS and others, behavioral data becomes an essential component of the overall surveillance package. In low level epidemics, good behavioral data serves as an early warning system, a means for determining where to direct resources to keep prevalence low, and a tool to advocate for immediate action. In concentrated epidemics, solid behavioral data becomes central to formulating effective programs and focusing resources where they will have the greatest impact. And in generalized epidemics, behavioral data additionally contributes to understanding the underlying causes of changes in HIV prevalence, which is essential to keeping the response relevant to evolving circumstances. In all types of epidemics, tracking behaviors over time serves as a significantly more sensitive indicator of the effectiveness of national program efforts than serological HIV data, which respond only slowly to changes in behavior.

However, limited experience with behavioral studies and a lack of understanding of what is meant by behavioral surveillance have slowed the introduction of behavioral components for national surveillance systems. Accordingly, most countries are still at the very early stages of incorporating behavioral data collection systems into their overall surveillance systems. To date, only a handful of countries have included behavioral surveillance in their national surveillance systems (e.g., Thailand, Senegal, Cambodia, Hong Kong, and India (the state of Tamil Nadu)), but the content, methodology, and use of the findings for program direction vary substantially from place to place.

### *Factors Distinguishing Behavioral Surveillance from other Behavioral Methodologies*

A number of behavioral study methodologies may be of value to national programs at various points and stages of the epidemic. These include:

1. Rapid assessments, social and geographic mapping of risk sites and vulnerable populations, and different qualitative research approaches (e.g., in-depth interviews, focus groups, and anthropological observation).
2. General population surveys, including specialized surveys among youth, who are often at high risk of HIV and STD.
3. Repeated behavioral surveys in specific sub-populations asking a limited number of pertinent questions (behavioral surveillance).

Each of these approaches has its uses in improving national responses to HIV and AIDS, but each also has limitations or drawbacks.

Rapid assessments, mapping, and qualitative approaches are comparatively inexpensive and can assist in quickly assessing risk behaviors and identifying important sub-populations to be addressed in prevention programs. However, unless they are conducted by trained personnel with the active involvement of the relevant communities or if they fail to follow-up inconsistent or unclear findings (detected by triangulating behavioral and epidemiological data from different sources), they may give misleading, biased, or incomplete results.

Well-designed and carefully pre-tested general population surveys can be very effective at determining levels of risk behavior in the population at large or levels of bridging between the general population and certain more vulnerable populations. However, they are inefficient and ineffective at determining what is happening among vulnerable populations which are often small (as a proportion of the overall population), stigmatized, or hidden from view. Because they require a good sampling frame (usually household based), they are costly. This means that more often than not the instruments are complex and lengthy, gathering as much information as possible, since they cannot be done very frequently (typically no more than every third or fourth year on a large or national scale). The complexity of the instruments and their analysis often produces long lead times (two years or more in some cases) in the analysis and dissemination of the findings.

The final methodology listed above is what is has come to be known as *behavioral surveillance*. Distinguishing characteristics include:

1. It is usually conducted in a limited number of sub-populations which are seen as the most relevant to the progress of the epidemic locally,
2. It uses consistent (but not necessarily totally representative) sampling frames constructed in some manner and is repeated at periodic intervals,
3. In order to contain costs, it generally uses a relatively short instrument, gathering roughly ten or so key behavioral indicators relevant to the population in question and some sociodemographic information, and
4. The results are disseminated quickly to those in a position to act on them.

The behavioral data needs of national programs will vary by what has been done in the past in that country and by the stage of the epidemic (see UNAIDS 2<sup>nd</sup> Generation Surveillance write-up for more details). For example, all countries will benefit from a good review of what behavioral data has been collected and a subsequent rapid assessment if one has not been done before. Otherwise, countries may waste valuable resources researching things which have already been studied and fail to collect essential information on key sub-populations. Few countries have conducted general population surveys, yet they form essential baseline information for determining the impact of overall prevention efforts in the future. Such surveys are particularly important in countries which have moved to either the concentrated or generalized phase of the



epidemic. Properly designed behavioral surveillance will be of value in any stage of the epidemic since it will help in tracking behavioral trends when HIV prevalence is too low to show measurable changes (low level epidemics) and it will clearly exhibit behavioral changes occurring in response to prevention efforts in more advanced (concentrated and generalized) epidemics, long before HIV prevalence begins to change. The remainder of this paper will focus on behavioral surveillance systems and some of the key issues facing those trying to implement them.

### *Purposes of Behavioral Surveillance*

Well designed and locally relevant behavioral surveillance as a component of national surveillance programs can serve a number of important purposes:

- *It assists in the targeting and evaluation of overall prevention and care programs on a community scale.* In early epidemic situations where HIV prevalence is still quite low across the board, behavioral surveillance can help to identify and focus attention on those sub-populations with higher levels of behavioral risk where prevention efforts will have the greatest impact. In high prevalence situations it can help to identify persistent risks or areas where care is currently inadequate, requiring additional attention and resources.
- *It provides an advocacy tool for increased resources and expanded responses.* By highlighting areas of behavioral risk, even in the absence of high levels of HIV, behavioral surveillance can support calls for increased financial and personnel commitment to addressing HIV issues. Highlighting of behavioral risk, especially in politically important sub-populations such as workers in a critical economic sector, can draw attention to the need for a stronger response. Finally, it focuses attention on the continued existence of risk behavior, keeping it on the public agenda.
- *It provides much needed indicators of progress for national programs and helps build support for continued prevention and care efforts.* One of the biggest problems with HIV prevalence is that it changes so slowly. National programs may have substantial prevention success, but it may be years before this is reflected in HIV prevalence figures, making it difficult to demonstrate to government officials and donors that they are making progress. Behavioral surveillance, since it monitors the very behaviors programs are attempting to change, can be used to demonstrate the success of prevention efforts and emphasize the importance of sustaining these efforts.
- *It can help to interpret changes in prevalence in more advanced epidemics.* Because prevalence may change due to a number of factors which are unrelated to prevention efforts (e.g., mortality, changes in the underlying population sampled, expanded recruitment into testing, changes in the coverage of the surveillance system, etc.), apparent slowing in the rate of growth or declines in prevalence may not be related to behavior change. Complementary behavioral and epidemiological surveillance can

give a direct indication of whether behavior change is influencing observed prevalence changes.

## *Issues in the Design and Implementation of Behavioral Surveillance*

However if behavioral surveillance is to achieve these purposes, a number of critical issues must be taken into account in designing and implementing the system. (NOTE: These are in addition to the basic issues of sample design, methodology, etc. which have been extensively discussed in the papers referenced at the end of this document.)

### *1. Choosing and working with relevant sub-populations for behavioral surveillance in the local epidemic.*

Any country's HIV epidemic really consists of a number of sub-epidemics. HIV sub-epidemics take different forms in different countries because risk behaviors and the efficacy of past prevention efforts vary from place to place, from time to time, and from sub-population to sub-population, even within the same country. The design of an effective behavioral surveillance system that can assist national programs in setting directions thus requires a realistic understanding of the local behavioral situation and of locally relevant variations in risk behavior. This is essential for selecting the appropriate sub-populations for surveillance.

Unfortunately, in most countries scientific assessment of behaviors in both the general populations and specific vulnerable sub-populations tends to be the exception rather than the rule. Instead programmatic decisions are often taken based on politically or socially acceptable assumptions such as the almost universal: "our young people are not very sexually active", the frequently heard: "less high risk sex occurs in rural than in urban areas", or the commonly expressed: "we have very few men who have sex with men here". Few countries have representative data for the general population or can provide estimates of levels of risk or changes in behavior in important vulnerable communities over the last few years. In fact, there are often substantial political and/or social constraints on such data collection.

The limited nature of this available data often inhibits a country's ability to assess the potential for large scale HIV spread. In many countries at the low level or concentrated stage the "bridging" between particularly vulnerable communities and the general population is poorly characterized, making it difficult to assess whether a country will see explosive widespread growth of HIV prevalence or a much more gradual increase. This lack of knowledge does not allow realistic priority setting in HIV prevention efforts.

Without some knowledge of where risk really is in a given country, it becomes difficult to prioritize and determine the vulnerable populations on which behavioral surveillance efforts should concentrate. Thus, intelligently setting up a behavioral surveillance system may require some initial rapid assessments, a large scale population survey, and pre-testing in sub-populations which *may* prove

relevant. If this “homework” is not done first, the sub-populations selected may not provide useful information. For example, pregnant women have often been chosen as a behavioral surveillance population (to parallel epidemiological surveillance systems), but they are not particularly high risk and little useful data has come from these efforts.

Another critical issue in selecting the sub-populations for surveillance is access. In many countries, for example, men who have sex with men (MSM) have played a significant role in the epidemic based on reported AIDS case data. Yet, more often than not, national programs have had limited success in accessing communities of MSM for epidemiological or behavioral surveillance. Poor attitudes, long histories of stigmatization/discrimination, and mistrust of government based on negative past experiences have all contributed to poor relations. Yet, if MSM are indeed important epidemiologically, then prevention efforts must be developed in collaboration with them. In this situation, the building of good relationships for prevention efforts or the formation of partnerships with NGOs and CBOs working with these vulnerable populations might be the first steps to bringing them into a behavioral surveillance system. But these efforts must be undertaken with close attention to community concerns about further stigmatization and discrimination or they will further alienate rather than enlist the aid of these communities.

Thus, a number of issues arise in the selection of behavioral surveillance groups: How do we select them in a locally meaningful and rational manner? Should we be worrying about both urban and rural settings in designing the behavioral surveillance system? How do we build the partnerships and rapport needed to establish a behavioral surveillance system in vulnerable populations? How do we ensure no harm comes to the behavioral surveillance sub-populations as a result of our efforts?

## *2. Ensuring the quality of the data collection and analysis.*

Because the behaviors dealt with are sensitive, the issues of data quality require careful attention in any behavioral surveillance effort. Furthermore, the validity and reliability of behavioral data is often questioned by policymakers, so being able to address quality concerns must be a high priority. Careful design and pre-testing of the acceptability of the instruments is needed. The methodology of administration (face-to-face interview, self-administered questionnaire, etc.) must be chosen to minimize biases and maximize valid responses. Training and desensitization of the interviewers is required to ensure they are comfortable with the material and uniform in their administration of the questions. The data must be analyzed in context and the responses presented in a form that helps policymakers and program managers to make better decisions. Inconsistencies among different sources of behavioral data must be watched for and discrepancies resolved with follow-up work (triangulation). Where possible biological and behavioral indicators should be linked to provide validation.