

**ASSESSMENT
OF
AIDS PREVENTIVE STRATEGIES**

REPORT ON A WORKSHOP

sponsored by the
European Community Working Party on AIDS
(PMS Epidemiology and Prevention)

Luzern (Switzerland)
28-29 November 1988

Lausanne

March 1989

**INSTITUT UNIVERSITAIRE
DE MEDECINE SOCIALE ET PREVENTIVE
LAUSANNE**

*Adresse pour commande : Institut universitaire de médecine
sociale et préventive
Bibliothèque
17, rue du Bugnon - CH 1003 Lausanne*

*Citation suggérée : European Community Working Party on AIDS
(PMG Epidemiology and Prevention). -
Assessment of AIDS preventive strategies,
Report on a Workshop, Luzern, 28-29 Nov.88
Lausanne, Institut universitaire de
médecine sociale et préventive, 1989, 59 p.*

ASSESSMENT OF AIDS PREVENTIVE STRATEGIES

Lucerne, Switzerland
28-29 November 1988

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PREFACE

"Assessment of AIDS preventive strategies" was included in the framework of the research priorities fixed by the European Community's (EC) working party on AIDS research. One of the first activities in this context was the holding of a workshop on that theme in Lucerne Switzerland on the 28th and 29th of November 1988. More than 40 experts from all countries participating in the COST project on AIDS research participated in this discussion of fundamental problems in the evaluation of AIDS control strategies. One group looked specifically at the possibility of using epidemiological surveillance of sexually transmitted diseases as an indirect measure. The second group dealt with the evaluation of behaviour modification from the perspective of the AIDS epidemic.

The goal of the workshop was to foster an exchange of information among experts and to intensify collaborative efforts over the coming years on the European level. This goal was attained.

We wish to thank all participants for their active contribution towards the achievement of this goal and for their willingness to foster cooperation in the field of assessment on the European level.

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USE OF INFECTIOUS DISEASE DATA IN ASSESSMENT OF AIDS PREVENTION: PROBLEMS AND POSSIBILITIES

Summary

M. Böttiger

The HIV epidemic and the problems of evaluating an effect of preventive measures undertaken has led us to look for alternative possibilities of assessment. To assess the spread of the disease itself is, as we all know, difficult and not possible in many countries. Assessment through surveys has so far been the most common tool. How relevant these data really are for evaluation of the spread of disease is questionable.

A more objective method to estimate "risky behaviour" is to make use of statistics concerning other sexually transmitted and bloodborne infectious diseases. Such indirect indications are popularly called "surrogate markers". One of the aims of this meeting was to discuss the possibilities of using such surrogate markers. For this purpose I will first mention some different tools we may have today to monitor infectious diseases (Table 1). The most widely used method of monitoring sexually transmitted disease (STD) is some kind of numerical report system. Nominative reports and laboratory reports are also used.

Table 1 - Surveillance systems

Reports

Nominative	Full name Age and sex (with initials) Code	
Numerical	General From special physicians Clinics, areas, etc.	
Laboratory	Only positive reports All tests	
		Total Age and sex categories

Registration of complications:

- pelvic inflammatory disease
- AIDS
- late stage syphilis
- mother-child transmission

Cohort studies

- studies planned for this purpose
- use of specimens collected for other purposes

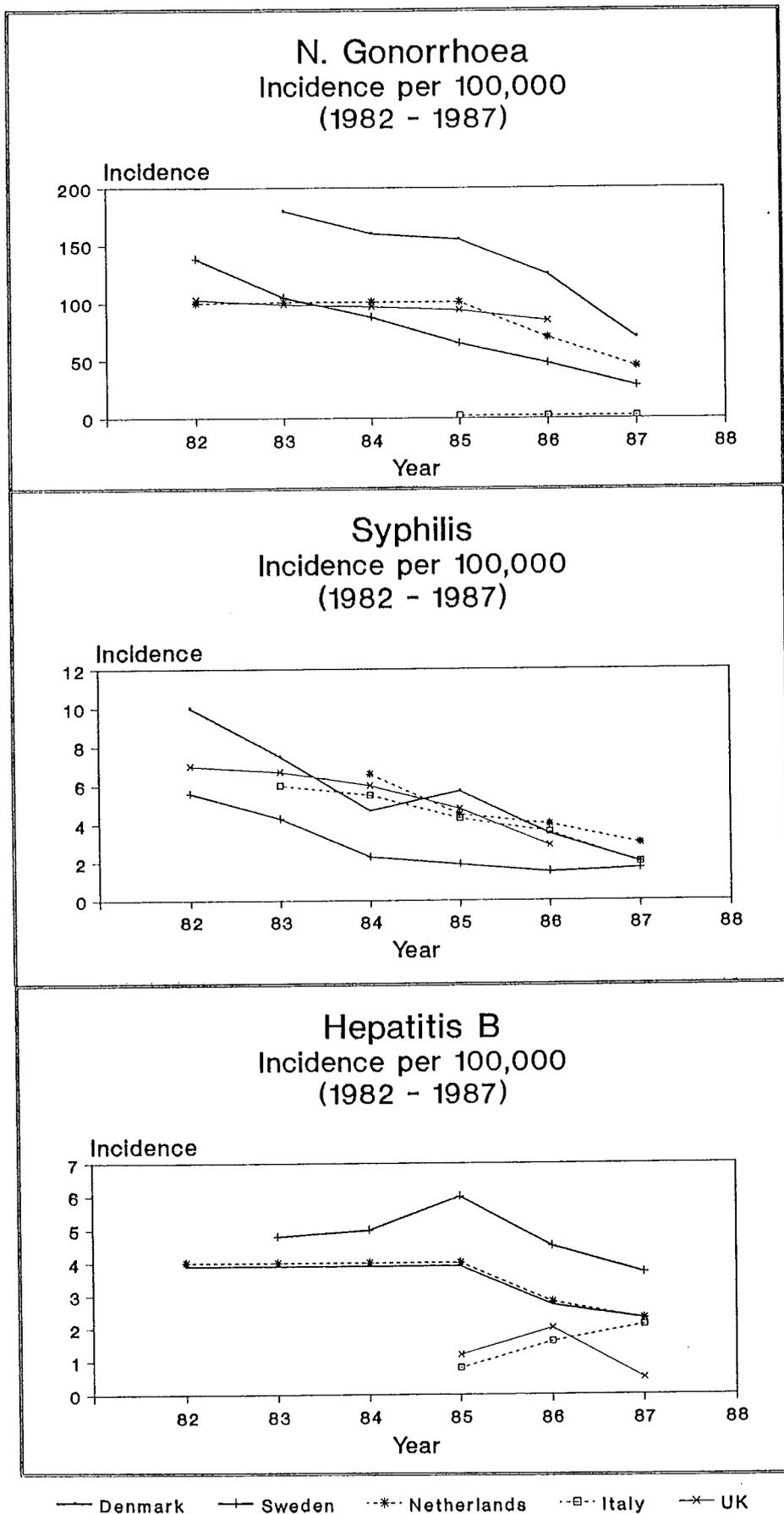
Specific studies in:

- STD clinics
- gynaecology clinics
- pregnant women
- recruits
- blood donors

Other studies

- of pathogens (isolation studies, antibiotic resistances, etc.)
 - serial serosurveillance in:
 - general population
 - subgroups
-

Figure 1.



Before this meeting a questionnaire was sent out to the participating countries asking about report systems used and trends concerning syphilis, gonorrhoea and hepatitis B. Answers received before or during the meeting are illustrated in Table 2. In at least 9 of the 15 participating countries some system of surveillance is working.

Table 2

	Syphilis	Gonorrhoea	Chlamydia	Herpes	Condyloma	Hepatitis B	HIV
Belgium	Mand* Vol Lab	Mand* Vol Lab	Vol Lab	Vol	Vol		-
Denmark	Mand Lab	Mand Lab	(Lab)			Mand	-
Italy	Mand*	Mand* Will be improved				Mand	-
Netherlands	Mand	Mand				Mand	- Spec. stud
Spain	Mand	Mand				Mand	(Lab)
Sweden	Mand Lab	Mand Lab	Mand Lab			Mand Lab	Mand Lab
Switzerland	(Vol)	(Vol)				Vol Lab	Mand
United Kingdom	Mand Lab	Mand Lab	Mand Lab	Mand	Vol	Vol	Lab
Finland	Mand	Mand				Mand	
France	3% of labs	3% of labs					
Portugal (no surveillance)							

poor response

Mand = mandatory

Vol = voluntary

Lab = laboratory

No information available from Germany and Greece

In the reports from a number of countries, figures concerning syphilis, gonorrhoea and hepatitis B (HB) were provided. These figures were recalculated to give incidence per 100,000 and are illustrated in Figure 1. Remarkable similarities were seen in the trends of notification in the participating countries, i.e., a decrease in numbers during the last 5-year period.

The figures for Sweden were further shown to give background information for a discussion of the different possibilities of using the reports of STD for different purposes when broken down in yearly distributions, age, sex, national origin, etc. The initiation of the HIV prevention campaign in 1983 in Sweden resulted in a sharp decline of syphilis among men who, for a number of years, had outnumbered women. A slight decline of hepatitis B was also noted after 1986 among drug users.

During the 1980s, diagnostic facilities for *Chlamydia* were gradually built up in Sweden. During this period, however, it could not be used to evaluate trends. *Chlamydia* antibody testing in women was tentatively used for evaluation of markers of infection as was herpes type II antibody testing.

The problem of using diseases that had already begun to decline before the HIV era was pointed out.

In the effort to continually refine use of surrogate measures of behaviour in the assessment of AIDS prevention certain suggestions were put forth for further discussion, specifically: to make more use of laboratories; to improve epidemiological data in reports from physicians; to involve STD clinics, gynecologists, midwives and infectious disease specialists; and where feasible, to make use of sero-epidemiology.

PROBLEMS IN THE USE OF BEHAVIOUR STUDIES IN ASSESSMENT OF THE PREVENTION OF AIDS

John Paul Vader, (Manuel Carballo) *

In the last few years there have been more and more references to assessment, monitoring and evaluation. Evaluation in some fields has become almost a specialty in itself, with groups of people drawn from the bio-medical and bio-social fields all professing to have a body of knowledge of, and insights into what evaluation is. There is often confusion when talking about evaluation because there are some basic questions that are never really answered. The first is "Why do we want to evaluate?" Many evaluations are done without ever answering, or even asking, that question. The second is "What is it exactly that we want to evaluate?" The third is "What do we want to do or what are we prepared to do with the results of evaluation?"

"Why should we evaluate?"

The answer is refinement and constant evolution of intervention projects, approaches and programmes. A prerequisite to that is an understanding on the part of a national body or the people responsible for a programme, that no programme is, by definition, perfect. All programmes and all interventions must go through a constant process of refinement. This leads us to a fundamental problem : many national programmes and many people involved with programmes and interventions are basically unwilling to accept that they have not devised the already perfect system and model.

"What is it that we want to evaluate?"

This question is difficult to answer. One must carefully analyze the underlying objectives of the programme itself. People who devise programmes or who devise and undertake evaluations must first of all be clear as to what the objectives of the programme itself are, and, once this is clear, what the objectives of the evaluation are. That prerequisite is rarely met. Few programmes are developed with a clear indication of what the long term goal is and what the intermediate or specific objectives of that programme should be. Part of the reason for that - and certainly in the area of AIDS - is that for a long time nothing was done. Then suddenly there was a surge of activity, a surge of guilt at not having done things. In the urgency to meet this fast-spreading epidemic, programmes were initiated in isolation on very much an *ad hoc* basis. Intervention groups did not give themselves the benefit of sitting back and questioning exactly what was going on. Programmes were initiated without sufficient care being given to what the sero-prevalence situation was, what was known about the epidemiology of the problem. Programmes were set up without sufficient thought being given to the constituency of society and to the constituency of so-called "high risk groups" or groups that have a commonality of high risk behaviours.

"What to do with the results of evaluation?"

Few, if any, national AIDS control programmes today are committed to a process of evolution, or to changing what has already been started or funded, simply because the results of an evaluation indicate that the direction being taken is not exactly the right one or that some groups that should have been looked at are being overlooked or that certain pieces of information are not appropriate for that particular society, etc. The question that has come up again and again - certainly in the area of primary health care - is that of national commitment to evolution and change. It is one that we need to impress on the evaluation of national AIDS control strategies and educational programmes. Unless there is this commitment to refinement and to change, all the evaluations that will be done over a period of time will be negated or

* based on the presentation given by M. Carballo

neglected. If the data are not going to be used in some systematic fashion, the end result will be a decreased interest in doing evaluation of any kind.

These are the first questions that are raised with regard to evaluation, in general, not just for the behavioural or bio-social area. The same goes for the bio-medical area as well. Sero-prevalence surveys are of no use unless someone is going to use the sero-prevalence data in a meaningful way. To do repeat sero-prevalence studies of a sentinel population is of no use unless those data are going to be used to give some direction to prevention strategies. And yet we know now, in a sense historically, that many sero-prevalence studies are done only to be reported and to show trends over time. They are not related to the on-going refinement of strategies and the direction given to strategies.

"What are the objectives of prevention strategies?"

In the context of AIDS, one could cite a number of preventive objectives. Each of these objectives carries with it different indicators, different implications for the design of programmes and for evaluation.

The first of course is the *prevention of primary infection*, meaning the prevention of initial exposure to the risk of HIV infection. The second could be the *prevention of secondary infection*, i.e., onward transmission from an already exposed individual. A third might be the *prevention of high risk behaviour* among individuals who are suspected or known to normally practice high risk behaviour. The fourth could be the *prevention of undue psychological morbidity* associated with HIV infection and AIDS. As we move into a second phase of the epidemic with its problems of case management, this is becoming increasingly problematic. Related to that is the *prevention of undue physical morbidity*: providing access to appropriate care and designing methods of providing for appropriate care to those who need it. Then there are such issues as the *prevention of discrimination* that takes us more into the legislative area. Another area that is becoming particularly critical is the *prevention of undue psychologically morbidity or "burn-out" among health care workers* and people associated with providing care and counselling in the context of HIV infection and AIDS.

This is not by any means an exhaustive list. It is simply to show and to suggest that when we talk about preventive strategies, we are covering a broad range of issues. Each of those issues carries with it implications for the content, for the groups, for the way in which the prevention is carried out and, henceforth, the way in which they lend themselves to evaluation, monitoring and assessment

Within each of these areas there are also a number of factors that govern how we look at those prevention strategies. These could be *political, social* or *epidemiologic* factors. Invariably there will be a mix of these, but with different weightings attached to them. For example, the whole question of prevention of undue psychological morbidity in terms of resource allocation carries with it tremendous political connotations. In the eyes of many policy makers, however, it seems to be one that is given very low priority whereas prevention of primary infection seems to hold high priority.

Level of Tolerance

Perhaps the most important aspect, however, is what we could call the *level of tolerance*, i.e., what are we willing to accept as normative in each of those areas? That will define what we want to prevent and how far we are willing to go in developing the preventive strategies. Underlying the planning process, in the minds of everyone, is some sense of what is acceptable at baseline. If we follow logically from the assumption that we have to set a normative ceiling in terms of what to prevent and how far to go in preventing it, then one of the problems with evaluation is that it assumes that we know what the situation is at time 1 and that we have some expectation of what the situation should be at times 2, 3, 4, etc. Within the area of AIDS, unfortunately, few programmes have had the opportunity of knowing what the situation was at time 1. Thus,

when we go on to do evaluations, we are in a sense using the first data-gathering exercise for the evaluation as a surrogate for the situation at time 1. This is one of the most unfortunate situations that we are faced with. Many of the evaluations that will be done really do not have a baseline with which to compare. In our group this afternoon, the question was raised of doing initial research *before* going on to develop a particular strategy. This will allow one to not only develop the strategy around a known, given and measured situation, but also to obtain that baseline at time 1 which will allow measurement of the impact and the effectiveness of the strategies.

There is also the assumption that the behaviour at time 1 can be described and disaggregated and can be measured in terms of incidence, distribution and significance for certain outcomes, such as the relative risk of HIV infection associated with those behaviours. Few interventions are, in fact, permitted that luxury, even in the quasi-experimental situation today.

From the point of view of the difficulties in using behavioural studies to assess intervention, the point that comes to mind most immediately is the fact that most of the behaviours that are associated with HIV infection and with AIDS are, by definition, highly private, and in some cases covert, in other cases tabooed, in still other cases legally proscribed behaviours. Thus, the notion of measuring these behaviours is by definition extremely difficult. The development of behaviour models and using behavioural research in evaluation must always be recognized as having that fundamental limitation. The indicators that we are looking at, the behaviours that we are trying to describe and which we are trying to measure are behaviours that limit how much information we can get on them. The challenge is to develop innovative methodologic approaches that permit an analysis of these behaviours in a way that would benefit evaluation. Drug injecting, frequent encounters with multiple sexual partners, relationships with prostitution, homosexuality and specific sexual acts are all areas that are very difficult to research. This was brought home recently in a discussion with a group of researchers and people who were going to do some evaluation of counselling in the African region. When we came to talk about homosexuality, there was an immediate resistance to talking about this. In fact, almost every one in the meeting said, "It's no use talking about that because it doesn't occur in our region". It was only the following day, when we were looking at some of the epidemiologic data, that they talked about the incidence of HIV in prison situations. It was mentioned that that was due to anal intercourse that occurs in prisons. It soon became clear that this practice was not limited to prisons, but was a wide-spread practice all down the coast in this particular country. We came back to say that it had been mentioned that there was no such thing as homosexuality in the area. The reply was "That isn't homosexuality, it's anal intercourse."

This illustrated the point of the conceptualization of a particular type of behaviour. Homosexuality, today, in a Western situation has all sorts of connotations - almost a politicization - a self-identification. It has connotations of a commonality of meaning and symbolism which cannot - in fact should not - be easily superimposed on situations in other cultures, where specific sexual acts may take place, but where all the conceptual baggage that goes with our notion of homosexuality does not hold. This is one of the problems that we will inevitably have in developing behavioural research cross-culturally and in multi-centre programmes.

The next difficulty we have in looking at behavioural models of evaluation is that, unlike areas such as EPI and control of diarrheal diseases, it has been very difficult to propose quantifiable objectives in AIDS control. In few AIDS control programmes have we received the definition, for example, of the goal of the programme, e.g., "By the year 2000 there will be X % of cases of HIV infection". The reason is simply that we do not have sufficient knowledge to say where we are coming from, where we are going, what are the different models of projection or transmission, etc. From an evaluation standpoint, this will always be a drawback, something that will prevent us from going on to evaluate in the same way that it would be possible in other health interventions.

"Should behavioural studies be used in evaluation?"

Focusing specifically on this, the following considerations need to be taken into account. Firstly "What are the sentinel populations or groups that can be considered representative of the larger population or as representative of agglomerations of at-risk individuals?" In the area of sero-prevalence, it has been possible to define certain sentinel groups that have been considered indicative of trends or of national situations. But in the area of behaviour we do not know enough to date to be able to pick certain groups or certain sub-groups that are likely to be representative of larger populations and from studies of which we would be able to extrapolate to larger populations. In the discussion this afternoon, the point was raised that men who self-identify as homosexuals are not the same as men who practice sex with other men yet who do not self-identify as homosexuals. If we select a population for study among homosexuals from subscribers to gay magazines - as is being done in many European countries today - , we must ask the question of how representative they are of a larger population which does not subscribe to those magazines yet which nevertheless is practicing sex with the same sex. This is a fundamental problem that we will have to deal with before we can go on to use behavioural studies appropriately in the evaluation of intervention programmes.

The second point is "How can we access groups that we want to survey without an implicit contamination?" This is something that is not peculiar to the area of AIDS. It is common to any behavioural survey. There is a dictum among many anthropologists that once you study a society or a group that society is no longer the same group that it was before you went in to study it. In any behavioural research endeavour, we need to be aware and be sensitive to the role that the survey plays in changing behaviour or at least in defining in a particular way the responses of those people whom we study or interview. There is contamination of recruitment and contamination of actual interviewer-interviewee relationships.

Quantitative versus qualitative research

The question of quantitative versus qualitative research has been very adequately discussed this afternoon. The main thing is that policy makers are not looking for qualitative results. The idea that behavioural research is a "soft" science is exacerbated even more when policy makers question results of qualitative studies not only because they are not representative of large groups but also because there is not an explicit and standardizable methodology behind them. That is not necessarily the case, but that is what happens in many situations. There is a genuine need for people to move to the quantitative area, but then once in the quantitative area, there is also the need to do fast surveys. This afternoon there was mention of a telephone survey of sexual behaviour. It is questionable whether money should be put behind a survey by telephone, totally anonymous, often occurring in a family situation where the telephone is in a central location in the house, and asking detailed questions about particular sexual practices, number of partners, etc. Yet this is one of the traps we are falling into with a lot of quantitative surveys.

The question of trends over time and evaluation of behaviour over time raises another issue. Any behaviour is going to be affected by a host of factors: legislative, fashion, fad, peer-group pressure, what may be becoming normative behaviour, what might be political initiatives, what might be inputs from media or schools, etc., as well as the structured intervention of a national AIDS control programme. We must exercise caution. On the one hand we must not judge AIDS control programmes without taking into account that broad spectrum of additional factors that may be influencing changes in behaviour. Yet at the same time we must be cautious not to undervalue the role that AIDS control and prevention strategies have had simply because we are also aware of the other social factors that are influencing behaviour. That is one of the phenomena that we are faced with. The answer eludes us, but when the time comes for some real hard evaluation to be made using behavioural data, this is going to be one of the factors or issues that is going to haunt us. Can we segregate all this and talk in terms of relative contributions made by different factors?

Conclusion

The main points then are 1) evaluation, as such, and 2) use of behavioural surveys in evaluation strategies. It is not to imply at all that evaluation is not useful. It is extremely useful. But it needs to be carefully defined in terms of its purposes and what is going to be done with the information and what the objectives of the programmes that are going to be evaluated are. It is not to say that behavioural approaches cannot and should not be taken into evaluation. They can be an extremely important contribution and are perhaps all we have at our disposal in some cases. But we have to recognize the very clear limitations to extrapolation from this. We have to be clear as to what the methodologic prerequisites of evaluation using behavioural models are. We need to be more flexible in terms of such things as impact and process evaluation. There has been a tendency, certainly in the area of family planning, to run down the notion of process evaluation as being second class, something that you do because you are not able to do impact assessment properly. Process evaluation is, in its own right, a series of impact assessments over time.

EVALUATION OF THE AIDS PREVENTION CAMPAIGNS IN SWITZERLAND

F. Dubois-Arber, Ph. Lehmann, D. Hausser, F. Gutzwiller

Translated from the French by Geoffrey Dyson

Introduction

At the very outburst of the AIDS epidemic in Switzerland, the public health authorities developed a programme to fight the illness which included an on-going evaluation of the efforts undertaken in the fields of prevention and education.

The Swiss Federal Office of Public Health (OFSP) defined a strategy for the fight against AIDS which covered epidemiological observation, public awareness and social support for members of the risk-prone groups, HIV sero-positives and the already ill. From the outset, the prevention programmes have been directed towards the general public and have been developed in co-operation with the Swiss AIDS Foundation (ASS). This independent organization, created in 1985 on the initiative of a homosexual journalist suffering from AIDS, is supported and subsidized by the Swiss federal government.

The educative and preventive campaigns are intended to favour the adoption of safe individual behaviour (protection), to avoid reactions of fear or panic based on ungrounded beliefs, and to avoid all forms of social stigmatization or ostracism directed against any of the marginal risk-prone groups, people with seropositivity or the already ill.

The first large scale preventive campaign, undertaken in the spring of 1986, was the mailing to every Swiss household of a booklet about AIDS which contained essential information about the biology and the epidemiology of the HIV virus, the possible sources of contamination and the appropriate means of individual protection: limiting and choosing sexual partners, the use of condoms, and the need to avoid syringe swapping (1). This operation was evaluated by the University Institute for Social and Preventive Medicine in Lausanne (IUMSP), as the first step in the on-going evaluation process set up by the OFSP. Its execution was based on a model which included variables in respect to knowledge, beliefs and attitudes with regards to AIDS, as inspired by the "Health Belief Model." A telephone survey of representative samples of the population, questioned both before and after the distribution of the booklet showed that the booklet had been well received, was read by over half the population and that knowledge about AIDS and its prevention were quite clearly improved for its readers (2). With basic knowledge about AIDS being acquired, there was a noticeable reduction in the occurrence of false beliefs concerning the risk of transmission of the virus through acts of everyday life. This first phase of information prepared a favourable terrain for the campaigns that followed.

In 1986, the OFSP asked the Federal Expert Commission on AIDS to set up a "think tank" (creativ team)" capable of conceiving and developing AIDS prevention campaigns in Switzerland. This body is made up of specialists from public health, publicity agencies, and includes OFSP and ASS representatives.

In February 1987, a press conference marked the launching of a multi-media national prevention campaign, under the slogan of "STOP-AIDS." It is to last for more than a year. This campaign is based on two main themes: the use of condoms in sexual relationships with multiple or casual partners, and the need to stop syringe swapping in the case of drug addiction. Two months later, a third theme was added, that of faithfulness between partners. The form of the messages is simple, clear and undramatic. The means of exposing the public to the information are manifold: posters, advertisements in the press, radio and television. Much educative material, created for the diverse target groups (youth, women, teachers who intervene in a social context) is progressively complementing the media campaign (3, 4).

At the same time, the OFSP asked the IUMSP to continue its evaluation of the entire prevention process. Obviously, the wide exposure of prevention messages in and of itself, does not guarantee the messages' acceptance within the population, how much less the adoption of a risk-free behaviour. All too often, campaigns are launched without enough thought being given to their pertinence, their acceptability and their impact. This project, however, with its global approach, constitutes a European first.

- to measure the degree to which the campaign's objectives have been attained,
- to contribute to its success by making the necessary adjustments possible by the detection of areas of resistance or of areas where effects are amplified. The group of evaluators is committed to regularly supplying the OFSP, the "think tank" and other interested parties with its results.

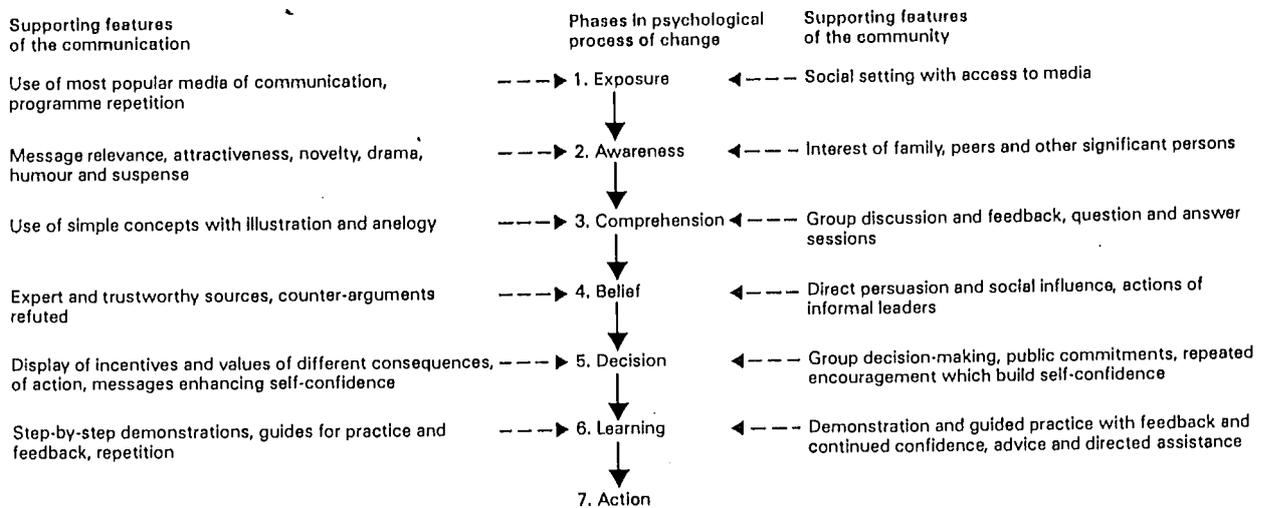
The Evaluation

The evaluation method used is based on a model developed by McAlister, among others, and which has been applied in the prevention of cardio-vascular disease in North Karelia (5). This model considers the process of behavioural change through the reciprocal influence of the campaign's internal factors (the form of the message, its exposure, its pertinence, the legitimacy of its initiators, and repetition) and environmental factors (access to the media, social resonance, reinforcement by social peers, ideas, dominating taboos and fears, etc) (Figure 2). This model is thus complementary to the "Health Belief Model" which considers change through the evolution of the subject's awareness.

Figure 2

MODEL OF BEHAVIOURAL CHANGE

The model used is based on the one developed by Mc Alister which considers the process of behavioural change through the reciprocal influence of the campaign's internal factors and environmental factors.



The different stages in behavioural change can be resumed as follows: First there is exposure to the message, the attention given to it and the understanding of its contents. Then comes a phase of change in attitude which consists of believing in the pertinence of the message and deciding to change one's attitude accordingly. Finally there is the learning stage and the putting into practice of this new attitude by changing one's behaviour. In order to make sure that the behavioural change is not short lived, each of the different stages must be passed with success.

The evaluation is laid out in such a way as to enable the examination of its different stages (6). It includes 13 inter-complementary studies concerning elements of the process (exposure to the message and the campaign's multiplying factors) and the results (change in attitude and behavioural change, condom usage) (Table 3).

Table 3 : Evaluation of the AIDS prevention campaign in Switzerland, 1987 : type of studies

Results measured quantitatively

Study 1 : Market study of condoms (sales figures, market structure)

Study 2 : Sexual behaviour and AIDS prevention among the 17-30 year old age group
(N = 2 x 1200)

Study 3 : Sexual behaviour and AIDS prevention among Sentinella doctors' patients (N = 495)

Study 4 : Knowledge and beliefs of young adults at the time of their conscription into military service (N = 1682)

Results measured qualitatively

Study 5 : Beliefs, attitudes and behaviour among 16 -20 year old adolescents in apprenticeship courses (N = 170)

Study 6 : Beliefs, attitudes and behaviour among heterosexuals with multiple sexual partners
(N = 42)

Study 7 : Beliefs, attitudes and behaviour among homosexuals (N = 873)

Study 8 : Beliefs, attitudes and behaviour among drug addicts in the care of outpatients services.(N = 37)

Study 9 : Beliefs, attitudes and behaviour among tourists who practise sexual tourism to tropical countries (work in progress N = 200).

Process studies

Study 10 : The public's exposure to the campaign (number of messages diffused and types of media used).

Study 11 : Multiplication of the messages, evolution of the news contents of the information concerning AIDS (Argus of Swiss press and electronic media)

Study 12 : Potential multipliers of the campaign's effects, informal leaders (interviews with parents, teachers, doctors, churchmen)(N = 150)

Study 13 : Analysis of AIDS prevention policies set up by regional authorities.

Behavioural change (dependent variables) is measured by the variation in the sales figures of condoms, the evolution in the number of sexual partners and the use of condoms among the 17 to 30 age group. The means and motives for these changes are analyzed by qualitative studies. Behavioural change is dependent on the total amount of preventive action (STOP-AIDS campaign and action taken by the multiplying factors whether they be stimulated directly by the OFSP or not) (intervention variables).

The first part of the evaluation includes four studies aimed at gathering quantitative results:

- analysis of the evolution of condom sales figures and the evolution of the condom market structure in Switzerland (the introduction of new brands, new means of selling them, such as by correspondence, vending machines, or in news agencies and in large department stores) (no 1.);
- telephone survey among a representative sample of the 17 to 30 year old population (N = 2 x 1,200 people), carried out in two stages: before the launching of the prevention campaign and eight months after. This survey measured the evolution of two important variables concerning the campaign's effectiveness: condom usage and sexual mobility (number of occasional sexual partners in a period of six months) (no. 2);
- survey among patients of the "notifying doctors' programme (sentinella)," also with a pre- and post-campaign phase and analysis of the same types of variables (no 3);
- survey among young male adults from the Ticino by questionnaire, querying points of knowledge and attitudes concerning AIDS, at the time of their recruitment for military service (no. 4).

The second step in the evaluation is devoted to the qualitative analysis of the results of the campaign in specific target groups. Those being considered particularly susceptible to having a behaviour liable to lead to HIV virus contamination (studies 5 - 9):

- adolescents from 16 to 20 year olds attending apprenticeship schools (no 5);
- people with multiple sexual partners (with great sexual mobility), considered as the "extreme" of heterosexual behaviour, any changes in their attitude and behaviour in respect to protection from AIDS being possibly applicable to the heterosexual population at large (no 6);
- homosexuals and bisexuals (no 7);
- IV drug users (no 8);
- tropical sex tourists (no 9).

In the absence of any socio-demographic data with estimates of the size of these sub-groups and which would allow the use of a quantitatively representative sample, a qualitative approach has been used here. Its purpose is to discover, rather than quantify, the emergence of any new behaviour or any resistance. An attempt is made to define the different stages and means of acquiring knowledge and behavioural change. The samples' validity and representativeness are assured by the greatest possible diversity of typologies within each group (life style, attitudes, behaviour, whether or not they are a part of specific sub-groups, or from different linguistic zones), which leads to the finding of "targeted" samples. For instance, in the homosexual study: recruitment was made initially by means of questionnaires in the specialized press, then followed a snow ball effect provoked by the first participants. During this stage, there was a search for certain missing profiles, in order to obtain as wide a sample as possible of all the different types of sensitivities to be found within the homosexual *milieu*. The data is gathered from in-depth interviews, sometimes coupled with questionnaires. The number of participants varies between 30 and 180 per group. The diversity of the data gathered is considered sufficient only once it is thought that any more would be redundant.

Finding such information is difficult due to the inevitable intrusion into the intimate aspects of these people's private lives. The variables that are used for the quantitative type studies remain unrefined and are thus rather poor as indicators to any real changes. It is through combining them with the qualitative elements which have much more information that the evaluation takes on its real meaning.

The third step in the evaluation concerns the progress of the campaign (studies 10 to 13).

Study 10 examines the progress of the campaign's message exposure (number of messages broadcast or published and by which media)

Study 11 attempts to determine the prevention message's exposure and its audience, the manner in which it is echoed and amplified by the mass media in the form of commentaries and in-depth articles. The instrument used to these ends is the *argus de la presse nationale* including the electronic media. Thus, measurements of message exposure (number of articles or programmes which households in any given regions may have access to) or the qualitative analysis of the contents (entire use of the message, modification or addition to its contents), can indicate changes in the way people think about AIDS (for instance: evolution in the notion of high risk groups, the appearance of cultural or moral resistance to prevention messages and the origin of such resistance).

In study 12 the emergence of the campaign's multiplying factors are sought out, that is those that can be called "informal opinion leaders": parents, doctors, churchmen, teachers. This study is based on the analysis of interviews with these natural leaders, recording their reaction to the campaign and their willingness to play an active role (positively or negatively) in the prevention of AIDS. For a message to be efficient and convincing, it must be confirmed by a credible source who is close to the subjects concerned (for adolescents, their parents or teachers for instance). The interviews were undertaken in three successive waves, before the campaign, one week after it had begun and six months later, in three groups of samples that partially overlap (part of the interviewees in the first wave are re-interviewed in one of the following waves).

Study 13 concerns the role played by the regional authorities (at the canton level) registering and analyzing AIDS prevention policies and action undertaken at this level (for example: sex education in schools, policies concerning drug addiction such as the "methadone" programmes or "unrestricted access to syringes" programmes, etc.)

Evaluation results in 1987

The campaign process

The press conference which launched the STOP AIDS campaign in the beginning of February 1987 was relayed by all the mass media throughout the entire country. The general reaction to the prevention messages overall was positive, with certain reservations being voiced by the ecclesiastical *milieu* which wanted to see more ethical recommendations. They emphasized however the clear distinction in roles between political and religious authorities by admitting that certain ethical and moral aspects of AIDS prevention come under their own sphere of influence and not that of the state. Moreover, the press guaranteed the continued exposure of the messages based on the AIDS theme with everything from fragmentary articles to in-depth articles going over the main facts and advise concerning the illness.

Informal opinion leaders (parents, teachers, doctors and churchmen) approved of the campaign, sometimes regretting its technical aspect (with reference to condoms) and its lack of any emotional quality. They declared themselves ready to answer any requests for information, help or advise from adolescents without however taking many initiatives of their own in this direction.

Everyone questioned had noticed the campaign's existence, and more particularly the posters. Only an infinite minority claimed to be shocked by the form or the contents of the messages. The poster under the slogan "Stay faithful" above the image of a wedding ring (this theme was added to the second wave of publicity messages) provoked some negative reactions from people who found its contents far too moralizing and who, in the case of homosexuals for instance, could not identify themselves with the symbol of marriage.

The usefulness of the prevention campaign is widely recognized and the credibility of its initiators (OFSP and ASS) is not doubted. Moreover a campaign is better received if its themes are taken up by local or specific voices. For instance, homosexuals will appreciate a prevention message more if it appears in a homosexual newspaper; adolescents will pay greater attention to a peer's experience in order to accept using condoms.

In terms of process, the campaign thus attained its objectives. Another aspect of key importance in the prevention campaign is the desired emergence of multiplying factors. This aspect is also off to a good start as many local actions (private or public, individual or collective) were undertaken after the launching of the campaign. Some of these are: the creation of AIDS ad hoc groups within hospitals, and within parent groups of the mentally handicapped, the creation of telephone information and support lines, improvements in sex education courses in schools, exhibitions on sexually transmissible diseases in apprenticeship schools, the installation of condom vending machines in discotheques, etc.

Changes in attitude and behaviour

The telephone survey carried out among a representative sample of 17 to 30 year olds before the launching of the campaign revealed that, in the six months preceding the survey, 18 % had had occasional sexual relations other than within a stable relationship. Of those, 67% never used condoms, 25% from time to time, and 8 % all of the time.

Eight months after the beginning of the campaign, 14 % had had occasional sexual relations in the preceding six months and condom use had increased: 38 % never used them, 45% from time to time and 17 % all of the time. The increase in condom usage is statistically significant.

The qualitative survey carried out in the different social groups chosen for this evaluation show numerous changes in attitude in respect to AIDS and the manner in which to protect oneself from it. There is a noticeable weakening of the taboos surrounding sexuality and sexual practices. People speak much more freely about sexuality (heterosexuality and homosexuality) in both private and in public. And the theme of sexuality and AIDS is frequently presented in the media.

The prevention messages (use of condoms, no syringe swapping, and faithfulness) have been accepted as being pertinent, which means that there is a positive attitude towards prevention.

Numerous cases of behavioural change were registered among the people interviewed. These changes generally concerned the use of condoms, but there was also the adoption of other means of having safer sex (decrease in the number of sexual partners, erotic play avoiding penetration, mutual faithfulness). It is noteworthy that individuals are adapting the prevention messages to their own personal situations, and are beginning to manage their own risk taking.

A large majority of the adolescents interviewed (apprentices) accept the pertinence of the message of the use of condoms during sexual relations with a new partner. A little less than half of those who had had sexual relations had experimented with condoms. Within this group, other means of protection were found which included that of evaluating the risk according to the "sexual history" of their partner. The condom's image is still bad (physical discomfort and discomfort in the relationship). To summarize, changes are taking place, and it is hoped that they will rapidly become an integral part of this group's "life style."

People with multiple sexual partners still have trouble admitting that they are running any risk. However, some of them are also in the process of accepting the condom (in spite of great resistance to its use), or penetration-free sexual relations (which is preferred).

Risk-prone behaviour is still widely practiced among drug addicts, particularly risk-prone sexual behaviour. In fact it is mostly those diagnosed as sero-positive who use condoms, rarely others. Syringe swapping appears to have diminished (within the group questioned: drug addicts in the support networks), but still persists if the drugs are present but the syringe is missing. The prevention messages do not go over well with this group and intervention here must be rethought.

The majority of homosexuals (85 %) claim to have changed things in their sex life. These changes began several years ago (more than 2 years ago for 57 %) after the specific campaigns carried out in the *milieu* but also because of the very proximity of AIDS. The noted changes (use of condoms, and the abandoning of

certain practices, etc.) seem to have affected all categories of homosexuals (age, social standing, diverse sensitivities) and all types of pick-up places. The condom has been well accepted, all the more so in that the diversity of homosexual sex practices leaves room for individual adaptation. It is noteworthy that 20 % of the homosexuals interviewed run some risks, and often this risk is only exceptional.

These recorded behavioural changes can be linked to the data concerning the distribution of condoms: in the first nine months of 1987, condom sales increased by 60 % compared to the mean 1986 figure calculated over nine months. The strongest increases took place in February and March where distribution was more than twice the mean monthly figure for 1986. A change in the structure of the market also took place (places of sale) with an increase of sales in the large department stores and by the appearance (still modest however) of other means of selling (vending machines and by correspondence).

There have been some noticeable phenomena of resistance towards behavioural change. They are often linked to a non-perception of risk. For example, risk of contamination is sometimes associated with groups and not behaviour: "AIDS is only to be found among homosexuals and drug addicts." Another example of non-perception of risk is among adolescents where faithfulness has a definition of exclusiveness rather than duration. They come into sexual maturity and are susceptible of having stable and faithful relationships, but which are successive. They therefore don't consider themselves unfaithful and underestimate the existence of a risk for themselves when they begin a new relationship in their quest for the ideal partner.

An inadequate evaluation of personal risk can also impede the adoption of protective behaviour in certain circumstances: a lack of vigilance or the ability to control oneself under the effect of alcohol or other drugs, nervous breakdowns, the state of "being in love", relief after having the results of a negative HIV test for example. The places which engender anonymous and furtive sexual practices such as public parks and toilets can also favour abandoning all protective measures.

The non-adoption of protective behaviour can also be linked to the effects of "jamming": contradictory or discordant information in the press, or mere rumors, may impede some people from considering AIDS as a sexually transmissible disease from which it is easy to protect oneself, and lead them into fear and frustration. Incorrect information, for instance, about the propagation of the HIV virus through kissing or shaking hands disqualifies the condom by placing the risk elsewhere.

There are very few reactions of ostracism from society towards risk-prone groups, people who are sero-positive or the ill. However, on a personal level, rejection of individuals can occur. The general opinion however remains one of moderation and openness, with few calls for discriminatory measures, isolation or constraints.

The conclusions which may be drawn after ten months of intensive prevention campaign are the following:

- The campaign attained its objectives, reaching the general population and target groups. Message exposure and amplification by the mass media was good.
- No strong resistance or opposition was created.
- Multiplying phenomena appeared (local actions, repercussions made by group leaders, etc.) and contributed to reinforcing the campaign itself.
- The sale of condoms increased.
- Noticeable changes in attitude and behaviour took place in the way of better protection in both the general population and in the groups which were specifically chosen for their probability of adopting risk-prone behaviour (adolescents, homosexuals, drug addicts, etc.), but this does not yet allow us to confirm that these tendencies will become generalized.

The evaluation's contribution to the rest of the campaign.

One may wonder what the potential and real use of such results may be. In the Swiss context where the prevalence of AIDS cases is the highest in Europe, where health institutions are mostly decentralized and where there is a tendency for social conformism, making a success of a campaign such as this which is open, pragmatic, and based on dedramatising the AIDS phenomenon is not a foregone conclusion. What is at stake, both epidemiologically as well as politically, is enormous. The need was to act quickly and correctly with the support of the vast majority of the population. For this reason, the following points, as communicated to the OFSP and the "think tank" are confirmation of the orientation taken and recommendations for the campaigns to follow.

1. The evaluation gives the necessary confirmation of the feasibility of such a campaign.

2. In all the interviewed groups, there was evidence of the perverse effect of "jamming" when divergent information was given. This reinforces the belief that a central reference centre (OFSP) is both necessary and legitimate, and that the orientations taken must be the object of a consensus, any ambiguity being a source of confusion among the population.

3. The noticeable emergence of numerous multiplying factors, in every *milieu*, capable of adapting and taking up the prevention messages must still be encouraged. We see the campaign's general messages being continuously in the background, while other multiplying factors come and graft themselves onto it. In this respect, it is important to point out that nearly all the interviewees who manifested behavioural change had two phases in the process of changing their opinion. Once they had acquired background knowledge about AIDS, it was the confirmation of the necessity of considering their own risk, as indicated by someone close to them (friend, parent, doctor) or by a noteworthy event (a case of AIDS or sero-positivity among their acquaintances for instance) which was decisive in their adopting protective behaviour.

4. The effort to integrate members of risk-prone groups in the discussions on health policy orientation concerning AIDS must be continued. At present, in Switzerland, social rejection and requests for measures of constraint in respect to these groups or persons are weak. This can certainly be attributed to the fact that these groups (especially homosexuals, but also prostitutes) were very active in the Swiss AIDS Foundation and have been associated with the campaign's "think tank", constituting a certain guarantee against the risks of stigmatization.

5. There are several indications that the efficiency of the prevention messages could be improved by slightly modifying its contents. It seems important that people be able to identify themselves closely with the messages and feel personally concerned. One of the obstacles to this is that the use in the educative material of accounts by the ill or those who are sero-positive, are always gathered among those who belong to the marginal risk-prone groups. This tends to reinforce the idea that aids is "someone else's problem". Along the same lines, the "faithfulness" message linked to the marriage symbol (wedding ring) should be replaced or complemented by a symbol suggesting more a satisfying personal relationship, which would mean wider groups of the population could identify themselves with it (homosexuals, adolescents). These few examples among others, were noted by the "think tank" which has decided to correct certain aspects of the present campaign and develop other aspects (especially prevention among adolescents by the adolescents themselves through a more adequate use of their meeting places).

In conclusion, AIDS is an illness laden with social and cultural taboos. The management of its prevention is facilitated by evaluating the prevention campaigns, allowing continual adjustment, with the aim of optimizing acceptability and efficiency. But beyond an efficiency measure, the evaluation also has "political" advantages. It can confirm and legitimate (or inversely, refute and doubt) the chosen orientation, both with respect to the population and to the authorities. This is all the more important in that the fight against AIDS will require considerable human and material effort over a long period of time. The evaluation process constitutes an essential contribution to the debate over the future choices in the prevention of AIDS in Switzerland.

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ASSESSMENT OF AIDS PREVENTION IN IV DRUG USERS

SUMMARY

J.A.R. van den Hoek

The main transmission route of HIV among intravenous (IV) drug users is the sharing of needles/syringes, but heterosexual transmission may also play an important role in the spread of the infection. Various studies assessing knowledge of HIV transmission among IV drug users show that the majority of them know the risk of sharing paraphernalia but fewer know about the possibility of heterosexual transmission.

In the behavioural studies so far emphasis has also been on the risk of needle/syringe sharing. Different types of studies have been carried out. The one most commonly used so far is the retrospective study comparing self-reported past IV drug use with present behaviour. Such a study also took place among IV drug users in Amsterdam as part of a larger epidemiological study. This study started in December 1985 to assess the prevalence, incidence and risk factors of HIV infections among different subgroups of drug users. Questions were asked about the IV drug use behaviour in the past six months and in the five-year period preceding entry.

The results were as follows :

During the 6 months before entry into the study a significantly larger proportion reported intravenous drug use at home and alone and a significantly smaller proportion reported daily IV drug use and the use of the same needle more than five times. A significantly larger proportion reported use of the needle/syringe exchange system (1). The risk reduction found in our study agrees with the results of other retrospective behavioural studies (2). A serious drawback of these retrospective studies is that participants have to remember behaviour of the past, long before the interview, and may have the tendency to make the past worse and the present better.

Cross sectional studies are also used to study behaviour, for instance in samples of IV drug users entering methadone programs or prisons.

Data of these cross-sectional studies are compared over time, but the comparability of these samples is questionable. In other words: is there a real change in behaviour or have different groups with different risk behaviour been compared. So far a few studies report behaviour change together with a relative stabilization of sero-prevalence rates. In New York City two research teams report a relatively constant rate of 55% to 60% HIV sero-positivity among persons entering treatment programs over three years (3).

Another way is to follow a cohort of IV drug users and assess their behaviour over time. In Amsterdam 263 drug users entered a follow-up study between December 1985 and March 1988. We were able to evaluate data from their second visit in 233 participants and data from a third visit in 165 participants.

This prospective study showed a strong reduction in sharing (borrowing and lending) needles/syringes. This risk reduction was mainly a test program effect and not a general time related effect. The change in behaviour appeared not to be related to the knowledge of HIV-Ab sero-diagnosis. Considering these results we concluded that voluntary testing programs, with extensive counseling and ample provision of clean needles/syringes, will contribute to the control of HIV infection in this group.

None of the studies so far were able to show lower rates of HIV infection among IV drug users who had changed their behaviour in comparison to those who had not changed their behaviour. The incidence rate,

however, is the only objective measure of self-reported risk reduction. Up till July 1988 we observed in our cohort study 10 sero-conversions among 148 sero-negative IV drug users, resulting in an attack-rate of 7.3% (C.I. 2.6% - 12.0%), after a mean follow up of 1 year. The number of sero-conversions and the duration of follow up is yet too small to draw further conclusions.

Prospective studies are difficult to organize - especially in IV drug users - and often conducted among selected groups of which the representativeness is unknown. Serological screening of IV drug users on a large scale is not possible. Therefore an attractive alternative may be the study of surrogate markers for HIV incidence in IV drug users (e.g., hepatitis B, endocarditis).

Regarding the risk of heterosexual transmission of HIV among drug users we looked into prostitution by addicted women and men in Amsterdam and found that prostitution was practised by many drug users. A group of 117 addicted female prostitutes was studied for HIV and STD incidence to assess the potential role of these prostitutes in the heterosexual transmission of HIV. Intravenous drug use was reported by 96 (82%) of the women. 35/117 women (30%) were HIV infected. All but one HIV-Ab sero-positives had been using intravenous drugs. The majority of the prostitutes (61%) reported more than 2000 customers in the 5 years preceding entry. During the six months preceding entry they practised mainly vaginal and orogenital contact and reported frequent use of condoms (90% and 65% respectively). Despite this frequent condom use, 81% experienced one or more STD in this period. Considering the prevalence of HIV and STD and the finding by others that the presence of STD may facilitate transmission of HIV, we concluded that the potential of HIV transmission from these prostitutes to their customers is clearly present. Hardly any data are available about non-commercial heterosexual contact in IV drug users (number of partners, frequency and type of contact, use of condoms, addiction of partner), not to mention data about assessment of the effect of safer sex campaigns in IV drug users. However, preliminary results make it clear that sexual contacts are not as infrequent among IV drug users as assumed while condom use in private partners is only practiced by a minority.

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BEHAVIOURAL RISK REDUCTION TO PREVENT HIV TRANSMISSION: UNITED STATES OF AMERICA

Jill G. Joseph

In examining behavioral risk reduction in the United States there are three issues which need to be considered, each of which is discussed below. The first is to establish and discuss the special issues which arise in the area in AIDS/HIV condition risk reduction efforts. The second is that of discussing substantive findings both in previously identified "risk groups" and in the general population. It is important to distinguish between progress which has been made in subgroups who have received specific and targeted information for a longer period of time and in the general population which has only recently been a subject of intervention efforts. Finally, methodological issues more generally applicable to a variety of population groups and social/political environments will be discussed; particularly emphasis will be placed upon design and sampling as well as assessment.

A. Contextual Issues

In order to begin it is necessary to establish why AIDS in the United States of America (U.S.A.) is in many ways unlike other health problems which have necessitated behavioral change. In particular, three characteristics of the situation need to be considered: biological, social, and preventive or educational. With respect to the biological characteristics of HIV and the resulting infection, the prolonged latency (known to be in the range of five to ten years as an average) coupled with the inability to recognize asymptomatic carriers create special problems. Although HIV antibody testing can generally distinguish those who are infected from those who are not, in the sexual and drug-sharing environments where transmission occurs the availability and effectiveness of such test information is questionable at best. Taken together these two characteristics remind us in many ways that HIV infection resembles both the features of chronic illness (long latency, insidious onset) and of infectious diseases (person-to-person transmission, probabilistic contact with the agent). In this regard special attention must be drawn to the importance of seroprevalence in determining the risk of infection both to an individual and of transmission within a population. We are accustomed to dealing with health problems where in the behavioral antecedents are both well documented (e.g. smoking) and where their relationship to illness is relatively invariant across time. Contrast this with the complexities of HIV transmission: in addition to behaviors which transmit HIV, seroprevalence in the group where the practices are shared will influence the probability of subsequent infection. In other words, it is not only what one is doing but with whom, at what time period, and where, which strongly influence transmission in the U.S.A. currently. Most notably, seroprevalence in intravenous drug users (IVDUs) is extraordinarily high in the New York City - Newark, New Jersey area but still comparatively low in areas of the Midwest and West. Similarly, to suggest that anal intercourse is a risk factor is accurate but ignores the question of seroprevalence in the groups where the practice is occurring. Most obviously, anal intercourse is not equivalently risky among homosexual men and among heterosexual couples because of differences in HIV seroprevalence. It must also be recognized, of course, that seroprevalence in turn is dynamic and is constantly changing. The effect of such complexities is potentially to make the communication of risk reduction messages more problematic and less effective.

Finally, of course, the recency of the syndrome and the need for a population to therefore quickly adapt to new preventive messages must be considered. This is particularly sobering when one considers the decades-long preventive effort focused on smoking cessation in the U.S.A. and its slow albeit steady success.

In addition to biological characteristics, social characteristics are particularly important in influencing intervention efforts in the U.S.A. Modes of transmission are stigmatized and the identification of this epidemic with male homosexuality and intravenous drug use has created special difficulties. Furthermore, HIV infection presents an intense threat; not only death itself but disability, disfigurement and dependence characterize the seemingly inexorable progression from the development of symptoms to the terminal

episode. The combination of stigmatization and peculiarly intense threat is problematic and makes the communication of health information considerably more complex. Furthermore, in the U.S.A. there continues to be an absence of consensus in the mass media regarding modes of transmission. While this situation is slowly improving within the last twelve months there have been articles in magazines which argue on the one hand that HIV cannot be transmitted to heterosexual women unless they engage in anal intercourse or experience vaginal trauma during rape and, on the other hand, that HIV is transmitted through sneezing, coughing, and sharing of utensils. This atmosphere of distention and debate makes it much more difficult for the public to understand and accept the necessity for behavioral risk reduction which may require considerable effort and even uncomfortable change. Should, however, the mechanisms of transmission be recognized and accepted the strongly moral, ethical, and religious overtones attached to the behaviors must then be considered. For many in the U.S.A. the only acceptable behavioral risk reduction strategy is that of abstinence. The well known injunction, "Just say no" represents the somewhat simplistic attempt to suggest that whether with respect to drugs or sexuality the best alternative (if indeed not the only acceptable alternative) is that of abstinence. Finally, in addition to all these complexities the emerging complexion of the HIV epidemic must be appreciated for its impact on potential behavior change. It is increasingly true that it is socially and economically disadvantaged minority populations who are infected and ill. Thus, in addition to the early association of the epidemic with particular behaviors, it is now linked to poverty and disadvantaged. This creates at least two problems. The first is that of providing appropriate, meaningful, and effective educational interventions among those who experience numerous other health problems and for whom the sense of control and hope may be extremely limited. The second is that of the further association of this epidemic with disadvantage and discrimination. In this regard communication of educational messages becomes more problematic in the broader population.

The third aspect of this situation which needs to be carefully considered is that of the preventive and educational messages themselves. There has been remarkably little specific and credible information regarding behavioral risk reduction. This is particularly lamentable in a country which has led the Western democracies with respect to the timing and extensiveness of HIV transmission. Nonetheless, it is only now that national public service announcements are being developed and aired which will provide even generalized exhortations to use condoms. Furthermore, when such information is available it is often vague, inexplicit or underdeveloped. Thus, it now may be possible for condoms to be discussed but ways in which they are to be applied, when and how to remove them, or instructions on how to adequately sterilize shared needles are certainly not. It is well established that the adequacy of response to a behavioral recommendation is related in large measure to its specificity and detail. It is lamentably apparent, then, that the failure in the U.S.A. to provide behaviorally explicit information can only decrease the likely success of our efforts.

One additional caution should also be discussed. It needs to be recognized that the sexual and drug-use behaviors associated with HIV are personal and private rather than public. While appreciating the extent to which all behavior is social, these behaviors nonetheless are potentially especially problematic. Even a moment's reflection on the intimate, often aroused, and private context within which specific decision-making is practiced gives some sense of the potential difficulties. Even the most explicit of interventions will probably be delivered in a context very different from the environment of decision-making itself. The interpersonal and individual factors which influence such "on the spot" decisions may be difficult to adequately identify or address using our established educational methodologies. This discontinuity creates special complexities and difficulties.

It is apparent, however, that in spite of these difficulties behavioral change is occurring. There, however, special difficulties created in the context of HIV regarding the maintenance of any behavioral change. Perhaps most importantly, we need to thoroughly understand that there is little or no reinforcement as traditionally defined available for those who undertake behavioral change. Most changes undertaken to address a health threat lead to some change which can be monitored and for which reinforcement is available. Changes in food intake lead to weight reduction with associated increases in physical attractiveness, well-being, and exercise tolerance. Similarly, even changes in smoking can alter exercise tolerance and pulmonary function. HIV infection, on the other hand, is avoided by the elimination or modification of sexual and drug-using behaviors which may be associated with pleasure, specific social

environments, and an entire "lifestyle". Their modification or elimination leads to nothing other than the absence of infection which can only be "monitored" by HIV antibody testing demonstrating (on a delayed basis six months later) the absence of infection.

In addition to the absence of reinforcement there is also demonstrable evidence that instability in behavior or recidivism characterizes behavioral change in response to HIV infection just as it does to other health threats. Data emerging both from San Francisco and Chicago in homosexual male cohorts make this point particularly strongly. In spite of the predictable nature of such recidivism, in the case of HIV transmission it represents special problems. In particular, given the probabilistic nature of exposure rather than the lifetime prevalence of exposure model, it is clear that even a single episode of recidivism may represent considerable risk of HIV infection. Furthermore, as seroprevalence continues to rise, however slowly, in the environment the risk of brief or even more limited risk activities may actually be greater than at an earlier timepoint. For those who are themselves infected, the biphasic nature of infectiousness implies that later periods of recidivism are potentially more hazardous than early. For these reasons recidivism and instability in behavior is especially problematic although an underappreciated problem.

B. Behavioral Change

While the special features of HIV infection/AIDS need to be recognized and argue against rapidly implemented or simple behavioral responses it is also important to understand the extent to which behavioral change has occurred in the United States. Included here are the most recently available reports of changes undertaken in both special risk groups and in the general population.

Among homosexual/bisexual men a recent review of eleven published reports revealed that behavioral risk reduction was occurring in each population studies. This was true whether cross-sectional or longitudinal methods were used and across a variety of metropolitan areas. The magnitude of this change was, however, variable with more extreme change noticed in the major affected centers such as San Francisco. Variability has also been noticed with younger men, non-Whites, those living in non-metropolitan areas, and bisexual men appearing to have changed their behavior less. This is consistent with a general impression that it is those who are peripheral to the gay-identified culture either geographically, chronologically, or psychologically having been less receptive to or aware of the intervention messages. As suggested above, the few longitudinal reports also draw attention to the problem of recidivism. Among IVDUs the early sense of despair and hopelessness appears to have been unwarranted as fairly consistent reports of early and continued risk reduction appear. The usual design in the smaller studies is a pre- and post-evaluation with delivery of a specific intervention such as promoting bleach use for sterilization, establishment of a needle exchange, etc. Four of the five published reports detected significant change and in the fifth the statistical power was sufficiently limited that it was unlikely that change could have been detected had it occurred. With respect to the IVDU population it is particularly important to recognize that IVDUs represent not only a group within which needle sharing is leading to transmission of HIV but also linked to neonatal transmission. In recent statistics, 80-90% of infected infants have parents who are intravenous drug users. This calls attention to the need for further careful investigations of sexual practices and HIV transmission in this population. It is lamentable that published reports have largely confined themselves to behaviors linked to needle sharing. This is, however, likely to be rectified in the near future as National Institute Drug Abuse studies currently being fielded begin to provide data concerning sexual behavior as well.

Apart from a mailing from the federal government within the past 18 months there has been remarkably little centralized effort in response to HIV infection. Instead state and local initiatives exist responsive to specific initiatives or legislative mandates. Furthermore, there have been specific impediments to the development of national advertising campaigns as suggested above. Only now are the first nationally aired television advertisements for condoms becoming available. Not only is the provision of educational messages but assessment also limited in the current political context. For example, federal review commissions are delaying the development and fielding of a study specifically designed to assess the prevalence of sexual practices in the general population. In general, while attitudes and knowledge are

easily assessed inquiries into behavior are much more problematic. There are, however, several measures of response to the AIDS epidemic which are available. Condom sales have been monitored and demonstrate considerable change. In a period 1981-1986 condom sales were stable at approximately 180,000,000 sales per year. In 1987 this figure doubled to 390,000,000 and data from 1988 are not yet available. While encouraging, aggregate sales data tell us nothing about the characteristics of those who are purchasing the condoms or, indeed, the extent to which they are being used. Similarly multiple private surveys undertaken in the last several years provide a relatively sober picture regarding response to HIV infection. In 1985 somewhere between 5 and 41% of respondents in various surveys reported some change in response to the AIDS epidemic; the most common such change was, however, avoiding public places. In 1986 various surveys reported that 7-18% were changing their behavior and the mechanisms cited were similarly ineffective. Of the small number (7%) reporting changes in sexual behavior approximately half reported using condoms. This means then that 3.5% of those surveyed were using condoms in response to the HIV epidemic. Data available from 1987 are more limited but present few changes from this picture. Consistent with these somewhat pessimistic findings are data regarding sexually transmitted diseases (STDs) which have increased dramatically since the period 1981. This increase has been particularly seen in the young adult and urban population, precisely the groups most at risk for HIV transmission. This is especially worrisome because data from the homosexual male community in San Francisco suggest that even as other STD rates may be declining HIV seroprevalence can continue to rise due to the dramatically different natural history of HIV infection.

In addition to this general overview of population-based change findings from our own research in a cohort of homosexual/bisexual men living in Chicago may be of some value. Of particular interest is the construction of a behavioral risk index (Table 4) which attempts to simultaneously examine partner type (monogamous/multiple), actual activity (receptive anal intercourse yes/no), and condom usage (yes/no). The purpose of this index is to move beyond a micro level examination of specific behaviors to a more comprehensive overview of factors related to transmission of HIV. As shown in Figure 3 when examined in the 353 men in our cohort which were originally seronegative seroconversion rates appeared to validate the discriminatory ability of this index. It was then used, as shown in Figure 4, to quantify behavioral risk reduction in the entire cohort of men seen at four semi-annual assessments. The impression that behavioral risk reduction is occurring is confirmed by a more detailed examination of specific sexual practices at the same four timepoints as shown in Table 5. Finally, it is possible to combine those men at no or low risk into one group and those at high or modified high risk into another group in order to describe the consistency of behavior across time. This is important because data describing aggregate changes will overestimate the extent to which behavioral risk reduction is occurring. This is due to the fact that individual instability in behavior is not considered. As shown in Table 6 a somewhat sobering picture emerges suggesting that in addition to the group at consistently high risk (16.7%) another one-quarter of the cohort is engaging in intermittent periods of high risk behavior. The point being made here is both methodological and substantive. Methodologically we must develop ways of meaningfully summarizing many aspects of sexual behavior which may be addressed in an attempt to reduce HIV transmission and we must furthermore attend to intraindividual patterns of behavior across time.

Table 4 - Behaviour Risk Index

<u>No Risk:</u>	Celibate
<u>Low Risk:</u>	If monogamous, no receptive anal intercourse or receptive anal intercourse with condom use <u>OR</u> If non-monogamous, no receptive anal intercourse
<u>Modified High Risk:</u>	If monogamous, receptive anal intercourse without condom use <u>OR</u> If non-monogamous, receptive anal intercourse with condom use
<u>High Risk:</u>	Non-monogamous receptive anal intercourse without condom use

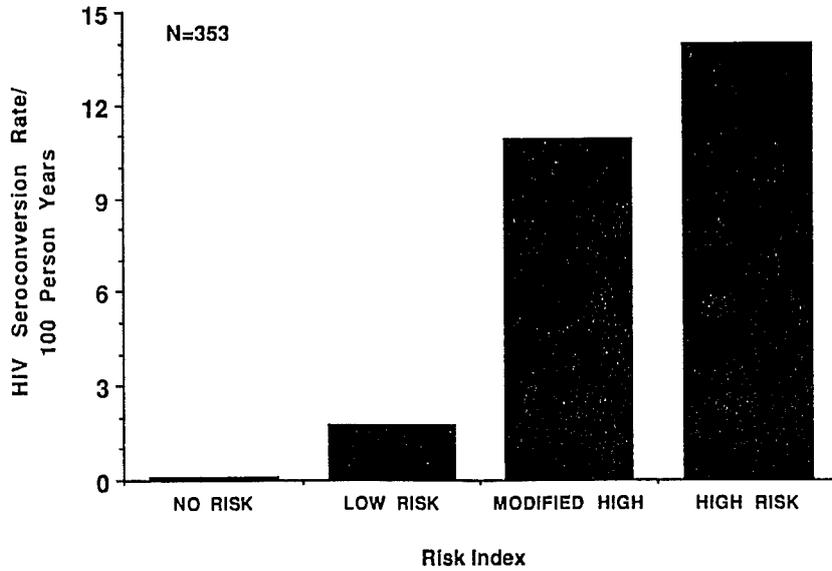


Figure 3 -
HIV Seroconversion Rates :
Relationship to Risk Index
Categories

Figure 4 -
Prevalence of Risk Index
Categories at Four
Semi-Annual Assessments
(Waves 1-4)

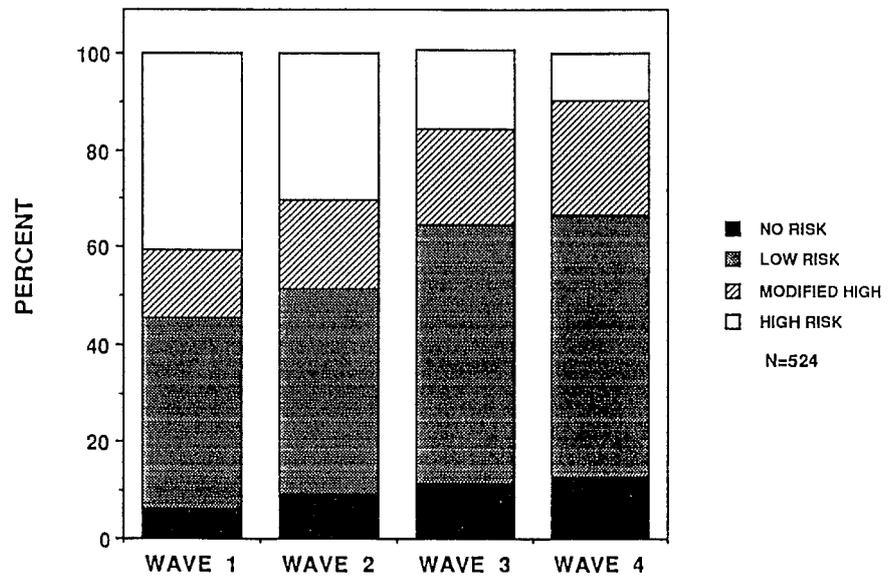


Table 5 - Prevalence of Specific Sexual Practices at Four Semi-Annual Assessments (Waves 1-4)

(N= 525)	Wave 1	Wave 2	Wave 3	Wave 4
Any receptive anal intercourse (RAI)	54.9%	49.3%	40.0%	38.6%
Condom usage during RAI	10.9%	20.8%	40.1%	58.2%
Celibate	6.35%	9.3%	12.2%	13.3%
Monogamous	15.6%	21.7%	27.2%	27.8%
Mean number sexual partners	6.1	4.4	3.4	3.4
Mean number anonymous sexual partners	2.5	1.8	1.3	1.3

Table 6 - Risk of AIDS: Individual Behavioral Patterns at Four Time Points

(N = 521)

<u>BEHAVIORAL PATTERN</u>	<u>PERCENT</u>
<u>Consistently lower risk behavior</u>	<u>29.9</u>
LLLL	
<u>Improving risk behavior</u>	<u>27.3</u>
HHHL	8.6
HHLL	8.1
HLLL	10.6
<u>Inconsistent risk behavior</u>	<u>26.0</u>
LHHH	2.3
HLHH	1.5
HHLH	5.0
LLHH	0.6
LHLL	4.2
LLHL	1.5
HLHL	2.1
LHHL	1.9
LLLH	3.5
HLLH	1.9
LHLH	1.5
<u>Consistently high risk behavior</u>	<u>16.7</u>
HHHH	

H = Higher risk (Combines "High Risk" and "Modified High Risk" categories of the RI)

L = Lower risk (Combines "No Risk" and "Low Risk" categories of the RI combined)

C. Measurement Issues

In order to discuss and compare responses to the HIV epidemic in different nations, it is necessary inevitably to also discuss measurement issues. Behavioral assessment may be undertaken for a variety of reasons including interpreting available seroprevalence data, ideologic investigations, evaluation of interventions, or providing data for the modeling of transmission. In considering the measurement of relevant sexual or drug-use behavior it is important to recognize that there are three broadly-based strategies for behavioral risk reduction. As suggested by the discussion of a behavioral risk index above, individuals may use one or more of these strategies at different points in time and each may be useful in reducing HIV transmission. The first is that of avoiding the behavior altogether, e.g. celibacy and avoidance of drug use. Politically popular in the United States, this strategy requires life-long adherence in order to be successful. The second broadly-defined strategy is that of selective avoidance. One can continue sexual practices but attempt to avoid partners one believes to be seropositive, not engage in receptive or insertive anal practices, or not share IV needles. In this case the general behavior (drug use or sexuality) continues but there is a more focused avoidance of behaviors associated with HIV transmission. Finally, it is possible to continue specific behaviors but modify them in order to reduce the risk of HIV transmission. In this case condoms are used consistently during intercourse or needle use is modified so that only sterile needles are used and/or needles are cleaned thoroughly with bleach solutions in between shared use. These approaches to behavioral risk reduction are important because they imply the monitoring of different and specific behaviors.

With respect to measurement itself it is clear that sampling and participation issues on one hand and assessment methodology on the other both contribute to our ability to monitor behavioral responses to the risk of HIV. The design of an adequate sampling frame is made more complex by our understanding that sexual and drug use behavior vary across the lifespan with important implications for the inclusion of specific subgroups such as adolescents, young adults, and divorced adults re-entering the group of those dating and having multiple sexual contacts. Furthermore, the importance of small subgroups cannot be overemphasized and even minimal non-participation may grossly bias any behavioral survey if such non-participation is differentially distributed so that the most important groups are not included. These concerns regarding sampling need to be combined with an appreciation of the lack of adequate data to construct sampling frames which target the groups of greatest interest: urban gay men and intravenous drug users.

Although the difficulties of sampling and the hazards of selective non-participation are numerous, a few lessons do emerge from efforts in the United States. Among the most important is that of securing community support for investigations and working with the target populations. Efforts to obtain data which are seen as intrusive are usually regarded with hostility while there is often enthusiastic support for research efforts which are well understood and in which the community is involved.

With the respect to measurement itself the questions are numerous and our answers are limited at this point. Current methodological research in the United States is attempting to investigate the impact of format (interviewer, self-administered, computer-assisted, etc.) as well as more traditional concerns regarding the format of questions and their placement within an assessment battery. It is apparent that careful consideration needs to be given to any culturally appropriate method which is likely to increase participant confidence in confidentiality and willingness to provide accurate information. The hazards of requesting information regarding remote behaviors needs to be emphasized; methods for facilitating recall of such events as first intercourse or specific sexual practices need to be seriously considered. For example, sex researchers in the United States are now interested in a life history methodology which routes the investigation of sexual behavior in the more natural context of relationships and their evolution rather than direct inquiry.

On the whole it is easy to focus on the difficulties of assessment which have been alluded to here. There are clearly a complex series of technical and methodological issues which need to be seriously addressed. However, it must be emphasized that the concerns regarding sampling and participation are equally fundamental. In our concern with technical issues such as the development of response options it is easy to overlook more fundamental questions such as access to the populations of interest.

In conclusion the progress which has been made in the United States with respect to the transmission of HIV can be documented in the first group of those infected and ill, homosexual/bisexual men. In intravenous drug users there is evidence of behavioral change but seroconversion rates in major metropolitan areas continue to rise virtually unabated. In the broader group of the heterosexual population little progress has yet been made. It is apparent that the unique problems of AIDS are both substantive and methodological. Those of use in the United States look to colleagues in Europe to teach us much about the development of effective public policy for stemming transmission of HIV in intravenous drug users. Together we may better be able to establish consensus regarding some of the methodological issues than any of us might do alone. Indeed, it is clear that in general this epidemic and many other health problems call for a new awareness of our interrelatedness as nations and our mutual dependence as human beings.

ASSESSING AIDS PREVENTION USING SURVEILLANCE OF SEXUALLY TRANSMITTED DISEASES:

REPORT OF THE WORKING GROUP

N. Billo, H. Zoffmann

Introduction

Health education is the only preventive measure available for HIV infection at this time. Its objective is to stop spread of HIV through changes in sexual behaviour and other life styles pertinent to risk of HIV infection. The impact of health education should ideally be monitored by measuring the incidence of HIV infection in various population groups over time. Due to the well-known difficulties in accessing groups with risk behaviour it is obvious that this is a very difficult, if not impossible, approach to getting information about HIV incidence. Nevertheless, HIV sero-epidemiological studies should be pursued and adequate methods elaborated. This important part of the assessment of the AIDS/HIV prevention is undertaken by the EC supported WHO Collaborating Center for AIDS Surveillance in Paris. This report will not deal with measurement of HIV sero-prevalence or incidence.

The immediate goal for health education is behaviour change. A direct measurement of the efficacy of specific activities can only be obtained through behavioural studies. An estimation of the efficacy of health education campaigns can be made, however, from incidence data of other infectious diseases transmitted through the same route as HIV. A reduced incidence in such diseases like gonorrhoea, syphilis, *Chlamydia* infections and hepatitis B indicates behaviour changes. From there it is assumed that the spread of HIV will also be reduced.

Most of the member states traditionally have surveillance systems for at least some of the sexually transmitted diseases (STDs). During the meeting it was evident, however, that in many countries STD surveillance is insufficient and in some countries it is non-existent. In contrast a few countries have good and reliable information on these diseases.

Therefore, the main goal of this working group was to come up with recommendations on how to develop and strengthen surveillance systems in order to get reliable information for the assessment of AIDS/HIV preventive activities. The aim of the group was not to come up with a proposal for an ideal surveillance system, but to develop surveillance systems capable of monitoring trends for STDs, with special emphasis on the "traditional STDs": gonorrhoea, syphilis and hepatitis B.

Recommendations

Improved surveillance

It was agreed that every new case of gonorrhoea (regardless of the localization of the infection) and all primary and secondary cases of syphilis should be monitored. The problem of nominator/ denominator was discussed in detail and it was suggested that attempt be made to get an estimate of this proportion in each surveillance system. The need for common diagnostic criteria was also emphasized. This is true especially when cases become rare.

Considering all these points the group recommended collecting the following data for every case of these STDs:

- clinical diagnosis or laboratory confirmation
- sex

- age or 5-year age group (< 15, 15-19, 20-24, etc.)
- whether the patient was infected inside the country or abroad.

The above mentioned data should be regarded as more or less "mandatory". The following information is desirable for all STD patients:

- sexual preference for male partners
- prostitution
- intravenous drug abuse
- other risk factors

For hepatitis B sex, age/age groups and information on intravenous drug abuse and prostitution are important.

This surveillance should be implemented in all countries at the latest by January 1990.

Other STDs

The group agreed that at this stage *Chlamydia* and *Herpes genitalis* infections, condylomata and non-gonococcal urethritis should not necessarily be included in the surveillance systems. However, serological surveys of *Chlamydia* in different parts of the population may give good information on sexual behaviour as studies in Sweden have shown. The group expressed the hope that, in the near future, some countries may develop collaborative studies with the research group in Sweden.

BEHAVIOURAL STUDIES IN ASSESSING AIDS PREVENTION STRATEGIES

REPORT OF THE WORKING GROUP

J.P. Vader, F. Dubois-Arber, F. Paccaud

Introduction

The task set for the working group on behaviour studies was considerably more modest than that set for the working group on sexually transmitted diseases (STDs). It was taken for granted that participating countries had much less experience in the realm of behavioural studies compared to the collection and interpretation of data on STDs. Therefore, the discussion was centered on sharing experiences and problems, on discussing methodologies, on defining the scope and setting the framework for the smaller working groups that would be called into being following the meeting and whose task would be to come up with more concrete proposals for international guidelines and collaborative studies.

During the early session, discussion and exchange of information was focused on three subjects:

- 1) existence and scope of prevention campaigns in the countries represented and whether evaluation and assessment were being carried out;
- 2) distinctions between process evaluation and outcome evaluation on the one hand and between quantitative and qualitative studies on the other;
- 3) populations definitions for intervention, study and evaluation.

Some of these topics are covered in detail in the papers by M. Carballo and Jill G. Joseph and will not be developed here.

The experiences of all countries providing information on the use of behavioural studies in evaluation is summarized in Tables 7a-1, which are included in the appendices. Vast differences were observed in how national and regional authorities have responded to the AIDS epidemic. Campaigns have been organized on a national level in some countries, but mainly on a regional or local level by others. In some countries campaigns have been carried out in an organized, systematic and targeted way, whereas others have been characterized by a much more spontaneous nature. Some have been mainly initiated in the public sector, others stem primarily from private organizations. Whatever the past experiences in national prevention campaigns, a common will for the implementation of national campaigns appears to be emerging throughout Europe.

Much of the discussion focused on what needed to be done during the next two years in order to insure collaboration and coordination of assessment work on the European level in the field of AIDS control.

Depending on the state of advancement of preventive actions and of evaluation and assessment in the different sub-populations considered, the main emphasis of work over the next two years will represent a varying combinations of the following three aspects: 1) sharing of protocols, so that from the outset studies are rendered similar, 2) sharing problems during the study so that collective wisdom and experience can be shared in addressing and resolving those problems in on-going research, or 3) sharing, disseminating and comparing results.

IVDU

In work among intravenous drug users (IVDUs), for example, intervention and assessment are in the pilot phase in many countries, whereas among gay men, studies are well advanced but results are difficult to compare. A network for the study of the epidemiology of HIV among IVDUs exists, both on a European

level and at WHO level, but that this is quite different from what is proposed. It is, of course, of fundamental importance to maintain close contact with this epidemiology network, but the main thrust and focus of the newly proposed assessment network would be to link intervention and evaluation studies among those working with IVDUs. In this sense, the epidemiology network would be a valuable asset.

In assessing prevention in this population, the group felt that we must move away from the easily accessible sub-groups, e.g., those who come to methadone clinics, or those who "shoot up" in official shooting galleries, since they are, no doubt, quite different from other sub-groups of IVDUs.

Migrants

As with other proposed subjects for further work by expert groups, the definition of this category was difficult. From a narrow standpoint, migrants would include guest workers and refugees, whereas a broader definition might include sailors, sex tourists, and other highly mobile groups. The problems raised by such groups could be looked at from the standpoint of the country of emigration or the country of immigration. Each of these different definitions or standpoints would imply specific problems for interventions and evaluation.

The main idea behind proposing this group was not so much that HIV prevalence is high in these groups, but rather that they represent a potential route of spread of the disease that cannot be ignored. The integration or lack of integration of migrant populations will create either barriers or channels for the spread of the virus. These need to be evaluated. Due to lack of understanding of the language in general or lack of understanding of the particular vocabulary used to discuss risk situations for the spread of AIDS, these sub-populations will often not be touched by campaigns addressed to the "general population" or to groups characterized by involvement in high risk situations. Other factors influencing the impact or acceptance of AIDS prevention campaigns among migrants are the different cultural backgrounds and/or the particular characteristics of the migrant status. A special effort must be made to devise approaches for these special groups. Here as elsewhere process evaluation is fundamental.

This particular problem is impossible to be treated on a strictly national level and urgently calls for international collaboration, cooperation and coordination. Connections must also be fostered with networks and agencies already working the field of migrant health in general.

Male Homosexuals

A network of researchers for this group also exists in certain parts of Europe, as well as a coordinating effort world-wide by WHO. It was pointed out, however, that although much is being done terms of intervention, evaluation and assessment are lacking in certain areas. This is a potentially crucial problem from a political point of view, as funding agencies are becoming more and more strict on the need for evaluation before funding is renewed.

While it was recognized that it may never be possible to identify the sampling frame for gay men, as with intravenous drug users, it is important to move away from the more easily accessible sub-populations of gay men, e.g., those who are active in gay organizations or who read gay magazines, in order to base evaluation on an increasingly more representative sample. A further problem in representativity is the aging cohort effect of prospective studies of gay men and the need to renew cohorts with younger men or to create new cohorts, so as to separate the effects of campaigns from the effects of change in behaviour due to aging.

One task which needs to be tackled, especially in this sub-population, is how to extract more information from existing studies. A particular area requiring further work is the question of predictor variables of behaviour change in homosexual men, i.e., what aspects of their health beliefs, motivations and attitudes are determinants of behaviour change. Since prevention activities have been going on for a longer time in this population, there is also the unique possibility of assessing longer term effects of AIDS control strategies that are not available in other targeted groups.

General population

An important element of this point involves a definition of "general population". This notion could be defined by the process of exclusion, e.g., those who do not belong to the specific groups involved in high risk situations or addressed by specific intervention campaigns. Alternatively it could be considered to mean the target population of general information and intervention campaigns, e.g., non-targeted interventions such as leaflets sent to all households or TV announcements aired on general broadcasting networks. It was emphasized, however, that there will not be complete overlap between the "general population" addressed by a general information campaign and the "general population" reached by a population survey. This non-overlapping must be considered in the work of evaluation based on such a survey. Consideration must be given to what exactly can or cannot be obtained from general population surveys: what types of analyses and interpretations are valid using these data and how they can be nuanced or complimented by other types of studies.

A further aspect of the evaluation in this "population" would be to assess the effects that either the epidemic, the various campaigns, or both have on social values and cultural norms - some of which may be only marginally related to the epidemic. Another could be addressing, in a tactful way, the blunt question "Who is having sex with whom?". This is fundamental, not only for the content and design of interventions, but also for assessing these interventions and for modelling the epidemic. It was also felt that an effort should be made to standardize at least some of the items along the lines of the protocol developed by WHO for the assessment of knowledge, attitudes and beliefs.

The question of the adolescent population was also discussed. Although it was recognized that there was considerable overlap between the adolescent population and the general population, there was also the possibility of considering adolescents as a population requiring specific methods of intervention and assessment. It was finally decided, however, that a separate working group on assessment in this sub-group should not be created.

The particular problems for assessment among prostitutes were also addressed, but again it was not felt that a separate working group should be created.

In discussions of all sub-populations, it was emphasized that the small working groups formed would contact existing networks (European and WHO) that are already active in different fields of the epidemic. Their tasks, however, would be to look at the work of these networks from the particular viewpoint of assessment. One of the tasks of the small working group would be to obtain protocols from other networks to see how they could be used for the goal of *assessment*. This will avoid wasting previous resources because of lack of coordination.

Assessment must be well-planned and must be credible. Doubt was expressed whether any assessment study would ever come to the conclusion that an intervention was useless. Whether this is true or not, the fact of including process evaluation as a fundamental part of the intervention allows rapid feedback and constant improvement of on-going interventions.

In the context of responding to the needs expressed during the workshop it was pointed out that the proposed collaboration project would be part of a concerted action grant from the European Community. The goal of "concerted action" grants is not to finance research, *per se*, but rather to bring together researchers on a European level, to facilitate cooperative and collaborative studies, to further networking and to provide for the administration involved in establishing and maintaining such networks. Different national research programmes are, however, informally obliged to give priority to the funding for the actual research involved in such endeavours.

Considering the specific question of assessing AIDS prevention strategies, such a coordinating rôle could be approached in two quite different ways: either by 1) developing a new collaborative study, with a new design and a new target population for implementation in all countries or, alternatively, 2) bringing together those who are already actively involved in on-going research and attempting to find ways of strengthening cooperation and rendering forthcoming results as comparable as possible. It was this latter approach that was favoured throughout the discussion, the goal being to identify parties working on similar aspects of the epidemic who could bring together experiences and data for assessment. It was obvious that study protocols vary widely, even among those studying similar target populations. One of the high priorities would be the rapid dissemination of results and the sharing of protocols and problems. In the course of this intensive networking activity, it may well be that collaborative studies for assessment will emerge, but this was not considered an immediate goal of the expert working groups. The situation will however, be very different depending on the population one is evaluating.

PLENUM DISCUSSION, CONCLUSIONS AND FINAL RECOMMENDATIONS

In addition to the specific conclusions and recommendations of the individual working groups, discussion in the plenum focused on the necessity of assuring the establishment and maintenance of close contact at all levels: the different behavioural working groups among themselves, the behavioural assessment working groups with the STD assessment working group and both assessment focus groups with the sero-epidemiology group working out of Paris. In this context, the workshop was able to benefit from the presence of Dr Brunet who spoke on the state of collaboration on the European community in the field of sero-epidemiology. Here, too, the situation in throughout Europe varies greatly from one country to another. The testing of blood donors is, at present, the only common denominator in all countries, and even there, complete information is not available from all countries, nor are the characteristics of blood donors similar from one country to another. The state of collaboration in matters of sero-epidemiology is at present less than optimal, and information on what is available in many countries is lacking. It is hoped that the development of assessment networks using behavioural studies and STDs will also lend impetus to the strengthening of the collaboration in sero-epidemiology as well.

The following conclusions were adopted by the workshop in plenum:

1. There is a need to gather existing experiences on assessment, to glean core elements from these experiences, and to disseminate them widely. In this way full advantage will be taken for AIDS control in Europe through integration of these core elements into on-going and future interventions.
2. There is a need for overall evaluation programmes to go beyond traditional high-risk groups. This would include development of reflections on such concepts as "groups with higher prevalence of high risk behaviour", "risk behaviour", "at-risk situations", as well as overlapping among these different concepts. It would be desirable to include research on determinants and predictors of behaviour and behaviour changes. Evaluation of intervention processes and of behavioural changes should be considered as well as prospective research on fields not covered by present interventions.
3. There is a need for further discussion and development of methodological issues so that results can be rendered comparable and trends monitored. This would concern such areas as how populations are defined, selection and sampling, theoretical models used, definitions of core variables, data collection techniques, as well as reflections on ethical issues involved.
4. In order to implement these points and advance future cooperation, it is proposed to form small working groups of experts presently working in the assessment of interventions among homosexuals, intra-venous drug users, migrants and travellers, and/or involved in the evaluation of "general population" campaigns. These working groups would be mandated to establish contact with existing networks, where available, or to establish new ones in order to respond to the points expressed above and to encourage international collaboration on the European level. Such collaboration, depending on the state of existing research, could involve exchange of information, definition of areas where further development is needed, or proposals for collaborative studies. These groups would, together with the overall coordinating centre, prepare a meeting to be held in 1990 and publish the results emanating from the project.
5. A small working group (3-4 persons) should also monitor the progress in the countries in establishing surveillance systems for STDs along the lines of the working group discussion, assist at national level if needed with technical support and expertise, and

continuously identify areas where additional research should be carried out on a multicentre basis as a concerted action to improve STD surveillance for the use as markers for changes in sexual behaviour. Examples of such research collaboration could be feasibility studies on *Chlamydia* infection in different population groups or surveillance of non-gonococcal urethritis at the general practitioner level.

Consensus was found on the above points and all participants expressed their agreement and willingness to participate in this project. Of fundamental importance, however, was that close contact be maintained, among the four behaviour assessment sub-groups, with the group working on using STDs for assessment and with the networks following the epidemiology and sero-prevalence of HIV. This would be monitored by the central coordinating agency for the concerted action.

ACKNOWLEDGEMENTS

Gracious acknowledgement is made to the European Community Working Party on AIDS Research for sponsoring this workshop, to Dr. John Paul Vader for his work as principal reporter for the workshop and editor of this report and to Ms. Doris Winkler and Ms. Simone Hubert for their excellent secretarial and organizational assistance.

APPENDICES

Tables 7a - I

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7a BELGIUM

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	General population	Youth	University Students	School Students
Year	1987	1988	1986-87	1987
Objective of the study	Evaluation impact of information campaign (leaflet + TV spots)	Background study to guide campaigns directed at younger people	Two KAP surveys of university students	Background study to guide associations (family planning, etc.) working in schools
Methodology (general)	Telephone survey	Personal in-depth interview		Questionnaire applied in the classroom
Population under study (N, sampling)	General population N = 1200 Random sample	Cohort 12-15 year-olds N = 800 Random sample		Young people aged 16-25 at school or university
Instruments			Factor analysis of risk perception	Factor analysis of risk perception
Variables	Reception and reading of leaflets. Perception, attitudes. Behaviour change intentions	Perceived and actual knowledge about sex, STD, AIDS, Sexual experience and practices	Sexual behaviour KAP Attitudes towards risk	Sexual behaviour KAP Attitudes towards risk

Other groups under study --

Other types of studies --

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7b. DENMARK

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages):

1985-88: Multimedia campaign among the gay population about safe sex and HIV

1986: Leaflet to all households about AIDS, prevention, transmission

1987-88: TV campaigns to the general population about prevention, condom use.

19868-88: Local campaigns (schools, general practice, social services, local media, etc.) about prevention and condom use

	General population	Youth	IVDU	Homosexuals	Adult men
Year	1986/87	1988	-	1988	1987
Objective of the study	Monitor general knowledge	Improve health education among school children	-	Monitor risk behaviour	Monitor risk behaviour
Methodology (general)	Survey (Telephone) 2x cross-sectional	Survey Cross-sectional	-	Survey cross-sectional	Survey cross-sectional
Population under study (N, sampling)	Random sample of Danish adults	Cluster sampling 45 school classes	-	a) Members of gay organizations b) Persons receiving gay newspapers	Random sample of men (16-55) N = 2000
Instruments	Questionnaire	questionnaire self-administered	-	questionnaire self-administered	questionnaire self-administered
Variables	knowledge about 1) AIDS 2) Channels of infection	knowledge, sexual behaviour, attitudes socio-demographic groups	-	knowledge, attitudes, sexual behaviour socio-demographic groups	sexual behaviour knowledge attitudes socio-demographic groups

Other groups under study:

- health professionals
- cohorts related to hospital departments
- patients visitng STD clinics
- prostitutes (male/female)
- local groups of IVDUs

Other types of studies:

Local studies related to local campaigns.

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7c. GERMANY (FEDERAL REPUBLIC)

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages):

	General population	Youth	IVDU	Homosexuals	Migrants
Year	Since 1985 14 studies	1987, 1988	1985-88	1987	
Objective of the study	Knowledge & attitudes. Behaviour change	Assessment of attitudes & behaviour. Improvement of school programs.	Assesment of behaviour change; risk reduction	same	
Methodology (general)	survey	survey	surveys	survey	
Population under study (N, sampling)	1000 to 3000 per study	770 pupils 1262 pupils 1200 students	different selected samples; one study stratified sample (N = 800)	924	
Instruments	telephone questionnaires; personal interviews	questionnaires; personal interviews	personal interviews	questionnaire	
Variables	knowledge & attitudes towards AIDS; behaviour change in the last 6 months,	knowledge, sexual experience, behaviour change reacting to AIDS	knowledge about risks, needle sharing, sexual behaviour, social support, behaviour change, prostitution	knowledge, attitudes, behaviour change, risk reduction because of fear of AIDS	

Other groups under study:

Other types of studies:

Evaluation of information programs:
 street-work, school-work, psycho-social counselling, etc.
 TV-spots, etc.

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7d. GREECE

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages):

1986: Leaflet to all households about transmission, symptoms, prevention. Leaflet for homosexuals, IVDU, given to those self-selecting for anti-HIV screening or counselling.

1987-88: TV spots for general public about heterosexual transmission and danger of needle sharing. Local campaigns.

	Youth	IVDU	Homosexuals	Registered Prostitutes
Year	1988	1988	1988	1985-88
Objective of the study	Determine knowledge & attitudes about AIDS	Determine knowledge, attitudes, & behaviour change	Determine knowledge & changes in sexual behaviour	Evaluation of an educational campaign
Methodology (general)	Qualitative study	Qualitative study	Qualitative study	Prospective study
Population under study (N, sampling)	5000 high school students in Athens	Emprisoned and entering detoxification centres for IVDU	Self-selected homosexuals for anti-HIV screening	350 registered prostitutes of Athens area.
Instruments	questionnaire	questionnaire	questionnaire	questionnaire
Variables	knowledge, sexual behaviour, attitudes	knowledge, attitudes, practices	knowledge, sexual practices History of STD	analysis of .. blood sample .. cervical fluid sexual behaviour

Other groups under study:

Other types of studies:

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process

Table 7e. ITALY

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	General population	Youth*	IVDU	Homosexuals**	Migrants
Year	1988	1988	1986-1987 (at local level)	1984-85 by gay organization (no evaluation)	---
Objective of the study	Assess KA changes after national information campaign	same	Monitor drug-use and sexual behaviour		
Methodology (general)	telephone survey (2x cross- sectional)	same	Pre-post test		
Population under study (N, sampling)	Random sample N=1000	same	IVDU of few towns		
Instruments	questionnaire	questionnaire	questionnaire		
Variables	knowledge about AIDS, transmission, discrimination problems, behaviour change	same	drug use/ sexual behaviour		

Other groups under study:

Other types of studies:

* from 1987 on at regional level

** at base level (Rome, 1983-88):
cohort study to assess HIV incidence
questionnaire to evaluate sexual behaviour changes

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7f. FINLAND

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	General population	Youth	IVDU	Homosexuals	Migrants
Year	1986/87	1986/87	--	1983	--
Objective of the study	Monitor knowledge of HIV-infection	same	--	Prevent progress of HIV-epidemic	
Methodology (general)	Direct Interview (partly by telephone)	same		Personal counselling. Interview.	
Population under study (N, sampling)	Stratified sample N = 2000	same		N = 250	
Instruments	Questionnaire	Questionnaire		Questionnaire	
Variables	knowledge of HIV infection, attitude	same		Sexual behaviour: sexual practices, condom use, etc.	

Other groups under study:

Other types of studies:

Cohort study of homo- and bisexual men.

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7g. FRANCE

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	----- General population	Youth	IVDU	Homosexuals	Migrants
Year	1987 ->	1987 ->	1987 ->	1985 ->	1988 ->
Objective of the study	Impact studies post governmental information. Socio-behavioural studies.	Evaluation of information programs	Evaluation of liberalisation of syringe access	Socio-behavioural study	
Methodology (general)	quantitative and qualitative	quantitative	quantitative and qualitative	quantitative and qualitative	
Population under study (N, sampling)	1000 + small groups	3000	200	3000 + 300	
Instruments	polls + interview	pre-post questionnaire	interview + questionnaire	questionnaires in gay press + interview	
Variables	depends on studies	knowledge behaviour	knowledge behaviour	knowledge behaviour	

Other groups under study

Other types of studies

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7h. NETHERLANDS

Short description of AIDS-prevention campaigns or actions:

from 1984: Among gay men, using gay newspapers, video tapes, leaflets and posters, plus introduction of anal condom.

from 1986: Among IVDU, using leaflets, education, free condoms, needle exchange.

from 1987: Among general population, using TV, radio, newspaper ads, posters, free condoms, etc.

from 1988: Among youth and migrants using TV, radio, newspaper ads, videotapes, hand-outs, education, leaflets, etc.

	General population	Youth	IVDU	Homosexual Men	Migrants
Year	1987 ->	1988 ->	1985 ->	1984 ->	1988
Objective of the study	Assessment of knowledge, attitudes, sexual behaviour, plus changes	1) Assess changes knowledge, attitude & sexual behaviour after TV program and hand-out 2) Assess knowledge, attitude and attention paid to AIDS in schools.	1) Assess prevalence & incidence of HIV in relation to sexual & drug-using behaviour (plus changes) 2) Evaluate use of needle exchange system	1) Assess prevalence & incidence of HIV in relation to sexual behaviour (plus changes) 2) Knowledge, attitude (change in) sexual behaviour	Assess knowledge attitude sexual behaviour
Methodology (general)	1) Telephone survey (cross-sectional), 4 waves 2) idem, 3 waves	1) Pre-post test control group design 2) Random sample among secondary schools (N = 4000)	1) Cohort study, volunteers 2) Cross-sectional study	1) Cohort study, volunteers (8 waves) 2) Panel study, snow-ball method (3 waves)	posttest only after TV program among random sample from population register
Population under study (N, sampling)	15-45 years N = 1000 (approx. for each wave)	1) 13-18 year n = 260 2) n = 1000; 5 teachers each school	1) n = 660 selected pop. from Amsterdam 2) n = 148, idem	1) n = 750 selected pop. from Amsterdam 2) n = 750 selected pop. all locations.	300 Turkish & 350 Morrocans (male & female)
Instruments	Questionnaire	Self-administered questionnaire	1, 2) Oral interview 1) Laboratory tests	1, 2) Self-administered questionnaire 1) Personal interview laboratory tests	Written and oral questionnaire
Variables	1) Knowledge attitudes 2) Idem + sexual behaviour	1) Attitudes, knowledge & sexual behaviour, 2) Knowledge, attitudes, degree of attention paid	1, 2) Knowledge attitudes, sexual & drug-using behaviour. Participation exchange systems 1) Incidence & prevalence of HIV & other STD	Knowledge, attitudes sexual behaviour. Incidence, prevalence of HIV & other STDs	Knowledge, attitudes & sexual behaviour

Other groups or types of studies:

- Cohort study among promiscuous (> 5 sexual partners) heterosexuals.
- Laboratory testing among selected population of male homosexuals donating blood.

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7i. SPAIN

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	-----	-----	-----	-----	-----
	General population	Youth	IVDU	Homosexuals	Health Personel
Year	1987-1988	1987	1987	1987	1987-88
Objective of the study	Information on HIV transmission and preventive measures	Inform school pupils at end of school year (14-16 y.)	Information on transmission and preventive measures	Information on transmission and preventive measures	Information on transmission and preventive measures
Methodology (general)	5 campaigns	Materials for teachers	Leaflet for prisons Leaflet for high risk persons	Leaflet for prisons Leaflet for high risk persons	Courses
Population under study (N, sampling)	General population and young people	Last year of primary school and secondary school	Prisoners Special groups	Prisoners Special groups	Health personel (doctors + nurses)
Instruments	Leaflets. TV, radio	Booklets for teachers and proposed activities for class work	Leaflets	Leaflets	Lectures, group discussions, distribution of written information
Variables	Condom use. Syringe/ needle sharing. Information on transmission and preventive measures	Information on ways of transmission and preventive measures	Special language used in leaflets	Special language used in leaflets	Ways of transmission. Ways of prevention. Non-transmission by social contact. Prevention of transmission to health personnel.

Other groups under study -----

Other types of studies -----

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 7j. SWEDEN

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	General population	Youth	IVDU	Homosexuals	Migrants
Year	1986-88		1987 ->	1989 ->	
Objective of the study	Impact of information campaign		Identified path of transmission		
Methodology	Questionnaire		Interview		
Population under study (N, sampling)	16-44 y.old Response rate 60%		Arrested IVDUs		
Instruments	Mailed questionnaire				
Variables	Attitudes Confidence in authorities		Needle sharing Coital behaviour		

Other groups under study:

Other types of studies:

Table 7k. SWITZERLAND

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

- 1985-88 : prevention in the homosexual scene (condom use, avoidance of some practices)
- 1986 : leaflet to all households (about: what is AIDS, transmission, prevention)
- 1987-88 : multi-media campaign aimed to the general population (about: condom use, faithfulness, no syringe sharing, situation without danger of HIV transmission)
- 1987-88 : multiple actions at the cantonal level (sexual education in schools, in professional groups, etc)

	General population	Youth	IVDU	Homosexuals	Migrants
Year	1) 1986 2) 1987-88	1) 1987 2) 1988	1987	1987	1988
Objective of the study	1) evaluation of knowledge changes after the leaflet 2) measure of attitudes and behaviour changes	to determine knowledges attitudes and behaviour about AIDS	to determine knowledges attitudes and behaviour about AIDS	to determine knowledges attitudes and behaviour about AIDS	to determine knowledges attitudes and behaviour about AIDS
Methodology (general)	1) telephone survey in a representative sample 2 waves 2) idem 3 waves	1) qualitative study 2) idem	qualitative study	qualitative study	qualitative study
Population under study (N, sampling)	1) 20-70 y.old N = 1056;1278 quotas method 2) 17-30 y.old N = 1200 quotas method	1) ados in apprenticeship N = 170 targeted sampling 2) ados in the "zone" N = 25	IVDU in ambulat. care (social) N = 37	homo and bisexuals targeted + snow-ball sampling	migrant workers targeted + snow-ball sampling
Instruments	1) questionnaire 2) questionnaire	1) questionnaire discussion group 2) in depth interview	structured interviews	1) questionnaires N = 800 2) in-depth interview N = 43	discussion group
Variables	1) knowledge about AIDS, and transmission 2) sex. relationship in the last 6 months, use of condom	knowledges attitudes behaviour	knowledges attitudes behaviour	knowledges attitudes behaviour sex. practices in the last 3 months	knowledges attitudes behaviour

Other groups under study:

1987 : heterosexuals with multiple partners; sex-tourists, young recruits, patients of Sentinella doctors.
1988 : health care workers.

Other types of studies:

1987-89 : process studies : study of the role of the medias, role of informal leaders, cantonal actions
1988 : process studies : medias, cantonal action, HIV test centres, role of doctors
1987-88 : condoms sale.

The evaluation programme will continue until 1991.

ASSESSMENT OF AIDS PREVENTION
Studies completed or in process.

Table 71. UK

Short description of AIDS-prevention campaigns or actions (when, target group, media used, type of messages)

	General population	Youth	IVDU	Homosexuals	Travellers
Year	1986 1987 1988	1988	1987 1988	1989	1988
Objective of the study	Evaluate national AIDS health education campaign	Same	Evaluate needle exchange schedule	Monitor response to problem of AIDS	Focussed mainly on holiday and business travellers No extensive evaluative research conducted
Methodology (general)	Random location: quota of UK population, rolling.	same	Service centered at point of collection of syringes	Focussed samples of gay men interviewed about health beliefs and sexual behaviour.	
Population under study (N, sampling)	Representative (quota) sample of UK population 8,000 per annum	same	Service users		
Instruments	Face to face interview, structured questionnaire	same	Face to face interview, in-depth, semi-structured	Face to face interview, in-depth, semi-structured	
Variables	KAB (dependent) General demographic (independent)	same	Use of service Condom use. Exchange behaviour Risk reduction	Health beliefs Several attitudes and behaviours	

Other groups under study:

Prostitutes. Health Carers.

Other types of studies:

Studies have been initiated in order to provide data to inform health education campaigns, in addition to those designed to evaluate (e.g., research into the informational needs of injecting drug users who do not attend exchange schemes, and into those of gay men who do not attend gay pubs and clubs, nor read the gay press).

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