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## Assessing AIDS/HIV prevention: What do we know in Europe?

### Summary

An EC concerted action on the assessment of AIDS/HIV prevention strategies was conducted between 1989 and 1992. The aim of this concerted action (CA) was to bring together researchers who are active in this assessment field, make an initial appraisal of the results of AIDS prevention efforts in various population groups in Europe and develop an assessment methodology. Five areas of study were selected for the CA:

- the population as a whole ("general population"),
- men who have sexual relations with other men,
- intravenous drug users,
- migrant populations,
- monitoring of sexually transmitted diseases (STDs) to determine changes in behaviour.

For each of these areas, a working group composed of the leading researchers in the field in Europe was constituted and commissioned by the project administration and coordination team to collate and analyse data on prevention efforts and their assessment in different countries of Europe. This review presents the main results from the groups responsible in each area in the concerted action. A number of general conclusions from the results of this concerted action are drawn.

Primary prevention programmes for HIV/AIDS have been implemented in most countries. Broadly speaking, these programs are operating at three levels of intervention:

- *Nation-wide campaigns directed at the population as a whole:* Most of these are multiphase campaigns aimed at providing information about HIV transmission and protective behaviour. They use the

various mass media as channels and are directed mainly at modifying sexual behaviour.

- *Community-based interventions aimed at various target populations:* These populations will have been selected because of their high risk of infection (gay men and prostitutes) and because their members are difficult to reach (intravenous drug users).
- *Individual counselling,* often supported by public funds or large

non-governmental organizations, but also conducted by health professionals or community leaders in their day-to-day work.

In terms of human resources and financial support, major efforts have gone into developing and implementing these preventive programmes. In most countries, however, less energy has been put into the evaluation of these campaigns. Yet it cannot be claimed that evaluation of AIDS/HIV campaigns is a new challenge in terms of methodology – standard methods exist which have been developed over twenty years and are used in other fields of prevention. Assessment of a prevention programme includes the three main steps:

- *During the development of the intervention programme,* a short-term assessment is made to check on the feasibility of planned prevention programmes and/or provide for rapid feed-back to the promoters of the programme so that they can make any necessary adjustments to the messages delivered by the campaign. This kind of evaluation, which is sometimes designated a *formative evaluation*, is carried out to inform and to guide the most effective initiatives, which are, typically, undertaken by

advertising agencies, it is already a regular feature of most existing campaigns.

– The second type of evaluation is typically performed *during the intervention* and is focused mainly on the way the programme is actually functioning. This *process evaluation* therefore tends to be concerned with questions regarding the types of preventive service actually delivered during the programme (e.g., number of condoms or syringes distributed or sold) and the proportion of the population actually covered by the intervention.

– The third type of evaluation is concerned with the *impact of the intervention*, and endeavours to answer the very basic question of whether the intervention makes any difference. This *outcome evaluation* is a major part of the evaluation process, but, since it necessarily presupposes the full development of the preventive programme, it comes relatively late. Although HIV seroprevalence is the “final” outcome indicator of any preventive programme in this field, it is, as an indicator, both too general and too distant. Intermediate and surrogate outcome indicators have therefore been developed. These are aimed mainly at collecting information on knowledge, risk behaviour and protective behaviour.

Although the application of this evaluation framework and related methods to the field of HIV/AIDS prevention has revealed substantial problems. Experience in several countries however shows that assessment of HIV/AIDS prevention can be carried out successfully if carefully planned and adequately funded<sup>1-5</sup>.

Recognizing the crucial importance of evaluation for optimizing the current preventive programmes, helping to enhance the success of future initiatives, characterizing the actual process of intervention and for identifying all

possible impacts of prevention, the EC working party on AIDS approved in 1988 a concerted action coordinated by the Institute for Social Preventive Medicine, University of Lausanne<sup>6</sup>. It began at the end of 1989 and was completed in 1992.

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For each of these areas, a working group composed of the leading researchers in the field in Europe was constituted and commissioned by the project administration and coordination team to collate and analyse data on prevention efforts and their assessment in different countries of Europe (mainly EC and COST countries).

This review presents the main results from the groups responsible in each area of the concerted action (see also Wellings, Pollak, Rezza et al., Haour, Renton et al. in this issue). A number of general conclusions from the results of this concerted action will be then drawn.

### General population

The aim of this group was to critically appraise public education campaigns on AIDS in different countries and the methods used in evaluating the course and outcome of these campaigns. The purpose of

this was to identify possible factors associated with efficacy, and thereby provide guidelines for future initiatives. The specific objectives were as follows:

- collect available *epidemiological data* on AIDS and HIV infection;
- summarize the *political and cultural context* in which prevention campaign initiatives had taken place;
- collect *relevant details of prevention campaigns*, including information on target groups, methods used (mass media, counselling, etc.), agency employed (communication experts, health care professionals, etc.), setting (schools, workplace, etc.), content (messages);
- identify the *chief agencies* initiating and involved in prevention campaigns;
- identify the *research methods* used in the evaluation, together with the scale, scope and budget allocated to such initiatives;
- identify the *findings of evaluative research* in relation to public response to AIDS education.

Though the available data did not allow answers to be provided to all the questions asked, some general conclusions can nonetheless be drawn<sup>7</sup>.

Virtually all European countries have launched prevention campaigns aimed at the population as a whole. These campaigns differ considerably with regard to time of launch, scale, frequency, the tone employed and the messages put across. In particular, certain countries (e.g. Denmark, Switzerland) have unreservedly adopted a strategy that is clearly addressed at the population as a whole, reasoning that AIDS concerns everybody. Other countries (e.g. Sweden, UK) have been more reluctant to adopt such an approach and have developed campaigns targetting specific segments of the population.

Likewise, the forms of the intervention vary from country to coun-

try, e.g. media campaigns, deployment of multipliers able to transmit prevention messages within specific groups (e.g. social workers teachers, community leaders), a more personal approach to prevention (through the intermediary of more privileged interlocutors such as parents and the medical profession). Some countries insist on carrying out organized, well-thought-out centralized campaigns while for other prevention is the sum of multiple, more or less coordinated, initiatives.

The content of the preventive messages and the tone employed in speaking of prevention also vary considerably (use of emotion, focus on life or death, positive or negative approach to sexuality, etc.). In some countries, a very pragmatic approach was adopted from the very beginning (e.g., encouraging the use of condoms: Switzerland, Denmark). Other countries have proceeded gradually (speaking first of all about the danger of AIDS or the need to take steps to avoid it, and, in a subsequent phase, presenting the means by which protection is afforded: France, UK).

The pattern of development and the actual size of the epidemic (occurrence of first cases, prevalence) did not play a major role in the setting up of general prevention campaigns. As Wellings shows, it is rather the social, political and institutional contexts which have had a profound impact on the way in which the different countries confront the problem of AIDS.

Despite these differences in the approach to prevention, rather similar developments have been observed everywhere (or at least wherever such data have been collected):

#### Knowledge of AIDS

A satisfactory level of knowledge concerning the main routes of

transmission was achieved at an early stage. Some gaps in people's knowledge still exist, particularly with regard to the degree of risk associated with blood transfusions, kissing and certain kinds of social contact. Nevertheless, it is difficult to interpret the data on incorrect knowledge since they generally require subtle distinctions to be drawn in the evaluation of risk (measurable risk within a group, "theoretical" risk not confirmed by observation [kissing], existing but extremely slight risk virtually irrelevant for public health in comparison with other forms of risk [transfusion in a country which warns and tests blood donors]). As a rule, these distinctions cannot be drawn in the context of a standard questionnaire.

Differences in knowledge which are apparent within a given population and which reveal variations in the information received are of greater interest, and such variations have been respectively observed (e.g. lower levels of knowledge in economically disadvantaged or marginalized groups).

Measurable consequences (e.g. ostracism of HIV-positive persons) of irrational fears attributable to insufficient knowledge have also been observed. Non-discriminatory behaviour appears to be correlated with awareness of high-risk behaviour, means of protection, and risk-free situations.

#### Behaviour

Despite differences in the approaches adopted, there is evidence to suggest that the behaviour of the population as a whole is beginning to change. For the moment, however, this evidence is limited.

It is difficult to make rigorous comparisons between countries because each one makes use of different indicators of behavioural changes. However, identical trends can be discerned in a number of coun-

tries (e.g., UK, Switzerland, Netherlands):

- Reported condom use increased between 1986–1987 and 1989–1990, particularly at the beginning of the period.

- This increase in condom use has been more marked in populations readily exposed to a potential risk of infection (frequent change of sexual partner, young people). In other words, there is an increase in appropriate use of condom.

- In certain countries, this increase in reported condom use may be correlated with an increase in the sale of condoms. This correlation, together with the similarity of the results stemming from different countries, suggests that these data can be considered valid.

- Other strategies aimed at reducing the risk of infection have been instituted simultaneously, such as reducing the number of sexual partners, having fewer but longer-lasting relationships, monogamy.

Some general points may be made about methodology:

- it is both feasible and acceptable to ask *direct* questions about sexual behaviour in the population as a whole. Different methods can be used (face-to-face questioning, telephone interviews). In addition, analysis of the trends based on indicators of behaviour makes it possible to demonstrate developments which cannot be picked up by questioning people about their intention to make changes in sexual behaviour or such changes themselves.

- In order to detect changes in the general population, large samples are necessary since the need to change behaviour (start using condoms, for instance) does not concern the majority of people if the reference period is short.

- The indicators usually selected often concern "typical" situations which are obviously associated with condom use and whose common denominator is either short-

ness of relationships or frequent change of partner. Other, less “typical” but more common, potentially at risk situations such as a succession of stable, monogamous relationships, are more difficult to investigate in surveys, posing great difficulties of formulation and requiring an approach of a more qualitative nature.

– The data currently available and the difficulty of comparing different countries do not permit any conclusions to be drawn about a causal link between the intensity of the campaigns, the form they take, and reported changes in behaviour.

### Homosexual and bisexual men

The major aims of this working group were to bring together a network of researchers working on AIDS prevention and evaluation of AIDS prevention among men who have sexual relations with men.

This group collected available data on<sup>8</sup>:

– Specific prevention campaigns aimed at homosexuals in different European countries.

– Studies conducted (with or without evaluative aims) among homosexuals using indicators such as life style, sexual habits, prevention behaviour, knowledge of and attitudes towards AIDS and prevention, etc.

– Data on the prevalence of HIV infection and AIDS for this section of the population.

– The risks (real or presumed) of stigmatization of the group by the population in general, the authorities, institutions, etc.

Analysis of the data collected have addressed the following questions:

– To what extent are prevention policies within the homosexual population in European countries comparable?

– What are the principal problems encountered during the campaigns and what are the main deficiencies observed? Are there sections of the population that are less affected (or concerned) by prevention campaigns? Do reactions of social stigmatization against homosexuals exist or, on the contrary, are there reactions of solidarity and group cohesion?

– Are there indications that AIDS prevention programmes had an effect on the behaviour of homosexuals? Can such changes be observed in all European countries or only in some? If differences exist, to what may one attribute them? Are there any arguments in favour of a causal relationship between prevention efforts undertaken and results obtained? What are the main problems mentioned by the people studied concerning the acquisition of protective behaviour, and inversely, what elements favour the adoption and continuation of protective behaviour?

– What research is needed to evaluate the effectiveness of protection among homosexuals?

Prevention aimed at homosexuals differs from that aimed at all other population groups by the fact that, everywhere in Europe, homosexuals have been the initiators and principal protagonists in prevention activities. This undoubtedly explains why the main motor of efforts to ensure prevention has not been the spread of the epidemic but the ability to react to it as a community. A number of social factors have therefore been the key determinants: level of organization in the community, ability of the representatives of the community to achieve recognition and to establish links with the health system, open-mindedness concerning homosexuality, existence of a health system which has experience in the prevention field.

Differences in the speed and scale of the response to the epidemic can

be understood in the light of the features described above. In Europe, the type of preventive steps taken, the channels used and the messages communicated have not been uniform despite the existence of a network of communication within the homosexual community. As far as the messages put across are concerned, in some countries the stress was put on avoidance of anal intercourse (with the risk that such advice might prove “untenable” in long term because of the radical change in sexual habits it requires). Other countries have – in more pragmatic fashion – stressed the use of condoms.

Despite these differences, the following constants have been noted after taking into account 14 European countries (in 1990) in which studies (evaluative or not) have been carried out among homosexual and bisexual men:

– A high level of information and awareness was achieved at an early stage, i.e. toward the mid-1980s. It should nevertheless be noted that the information has been disseminated in centrifugal fashion: from urban centres with well organized and integrated homosexual communities towards the periphery with its more discreet, even concealed, homosexual lifestyles.

– Changes in sexual behaviour have taken longer to become established. Nevertheless, by the end of the 1980s, the majority of homosexuals were not exposing themselves to the risk of infection with HIV.

– Combinations of strategies have been applied by individuals (use of condoms, or prevention strategies such as reducing the number of partners, avoiding penetration, etc.). Countries differ with regard to the frequency and type of preventive behaviour adopted (avoidance of penetration as opposed to use of condoms). Because of disparities in the way the data are collected, however, it is not at present

possible to state that the observed differences in protection between countries are attributable to differences in prevention policies rather than to methodological bias. A European study (a direct outgrowth of the activities of the working group) which is expected provide at least part of the answer to this question is currently in progress. This behavioural study uses the same “core” questionnaire in 8 countries.

- In countries in which it is possible to compare recent behavioural data with those collected either before the AIDS epidemic or in the mid-1980s, the trend towards preventive behaviour is evident, particularly between 1985 and 1987. From 1988–1989 on, the growth in the protection rate slowed down and has now stabilized at a level that is still less than optimal and perhaps even insufficient to check the spread of the epidemic, in view of the high prevalence of HIV infection in this population group.
- It is evident from a number of studies that the issue of long-term adherence to preventive behaviour is crucial, and that the exceptions to such behaviour, the “accidents” (e.g., tearing of condoms), or even the resumption of high-risk behaviour, are a reality whose impact on the development of the epidemic is difficult to measure. Longer-term studies are required. In several countries, nevertheless, the rate of seropositivity among the subjects questioned has not increased despite the increase in the numbers tested.

Currently, the main problem is the fragility of the progress made in the maintenance of protective behaviour just as much as in the continuation of preventive activities, be they information campaigns or more day-to-day activities such as individual counselling and listening. Conceding the difficulties of long-term action in the endemic situation does not mean that pre-

vention has failed but simply that it takes time and that the success rate, as in all other fields of prevention (and human endeavour), will never be 100%. Nevertheless, this misunderstanding occurs, particularly among people for whom a degree of “temporary opening up” to the realities of homosexuality was felt to be justified only by the urgency of the situation. In future, therefore, it may become more difficult to mobilize resources for prevention among poorly accepted minorities such as homosexuals and to keep an “open-minded” and nonstigmatizing dialogue going on sexuality, which in particular takes into account the realities of homosexuality in the adolescent and young adult.

Many questions have been insufficiently investigated or given too little weight by the promoters of prevention campaigns:

- Too little is known about what some authors refer to as individual risk management. Above all, it has been the subject of too few investigations. The subtle personal adjustments to situations which take account not only of the sexual but also the emotional aspect of relationships and of the experience of seropositivity are unsuitable for evaluation in terms of indicators. There is therefore a lack of repeated qualitative studies of the individual’s deeper adjustment to the realities of AIDS.
- Stigmatization at the individual and group levels, and discrimination, are aspects that have still not been sufficiently investigated and itemized (this applies particularly to political measures, decisions in the field of insurance and of social and human rights).

### **Intravenous drug users (IDUs)**

The aim of this group was to assess the extent to which the implementation level of the prevention strat-

egies have determined behavioural changes and/or modification in HIV trends in IDUs, and to analyse the different experience gained in the European Community in order to identify problems encountered and lessons learned during the implementation of the interventions. In particular, it was expected that the group should be able to answer the following questions after analysis of available data<sup>10</sup>:

- Are the prevention policies (both national campaigns and local intervention programmes) within the drug-injecting population in EC/COST countries comparable, and what are the best indicators for evaluating the effectiveness of prevention efforts?
- What are the main problems (political, financial, etc.) encountered and deficiencies observed during the campaigns/interventions?
- Is there any evidence that prevention of AIDS has had an effect on the behaviour of intravenous drug users, and is there any evidence of the effectiveness of specific prevention approaches? If differences exist, to what may they be attributed?

The task assigned to the IDUs group therefore depended to a large extent on obtaining data on the evaluation of prevention programmes aimed at IDUs as a process. In view of the extreme diversity of the possible approaches to drug addiction, even before the advent of AIDS, it was important to procure information on the establishment of AIDS prevention programmes, i.e., to ascertain the significance of harm minimization, the conditions under which the programmes have been set up, the degree of acceptance or resistance encountered on the part of the political and health authorities and the public.

The first observation is that such information is often lacking, and

that the processes involved in setting up the programmes are often poorly documented and belong to a grey zone in the literature. The programmes pertaining to risk reduction (harm minimization) appear to vary greatly; they are shaped considerably by local characteristics (so they are small in scale) and there is an element of chaos in the way in which they are set up. Because opinion is often strongly polarized on them, they are also continually being called into question, which puts their continued existence at risk. The programmes which involve street-work (outreach work) or which offer services close to the “scene” (premises for injection) have to operate in very difficult circumstances, not only because of the nature of their target populations but also because they are subject to particular types of pressure. They sometimes have to continuously justify their existence and they lack any safeguards (political and financial) that the work they have started can be further pursued, all of which are obstacles to taking a long-term view.

The following conclusions can be drawn regarding the impact of the prevention programmes:

- In the European countries, prevention through provision of sterile injection equipment has taken a lead over prevention by sterilization of the material and has been developed either by using regular channels (pharmacies, treatment centres) or by creating new ones (needle-exchange programmes). In contrast, less effort has been put into preventing sexual HIV transmission, an aspect that must be upgraded in this population group.
- Most drug users take advantage of the measures to prevent infection by the i.v. route (injection equipment, safe premises for injecting). They are therefore accessible to prevention measures and are aware of the AIDS risk to

which they are exposed. Studies based on behavioural data show that the use of sterile syringes has been adopted more rapidly and widely than that of condoms. However, comparable results obtained in a number of studies indicate that drug users have also started to adjust their sexual behaviour (use of condoms). Such preventive behaviour is more frequently mentioned by seropositive subjects.

- The HIV infection rate among drug users has fallen in several European cities. At the same time, the fears associated with the provision of injection material, e.g. increase in the number of new drug users, have not materialised.

- More (serological) tests for HIV infection have been carried out among drug users (and, for that matter, at the local level) than among homosexuals. Conversely, more behavioural studies (usually at the national level) have been performed among homosexuals than among drug users; data on the sexual behaviour of the latter group are still scanty and, in particular, insufficiently correlated with the findings of the serological studies. It is possible that drug users have tended to be considered as a captive population, irresponsible, unreliable in its responses and less likely to claim the right not to take the test. It is to be hoped that appropriate counselling and follow-up were systematically provided.

To conclude the review of this particular group, the widest possible dissemination of information is required, and particular efforts will still have to be made to initiate international, multicentre studies (particularly studies focused on behavioural aspects) which will go beyond the local studies hitherto undertaken. These epidemiological studies of behaviour must include information on the character of the drug scene, local drug-taking habits and the services offered.

## Migrants

The decision to include a working group on migrants in the CA was based on the fact that migration and the existence of quite substantial sections of the population of foreign origin, integrated to varying degrees, are an important phenomenon in European countries. Among the various aspects of migration, immigration (recent and less recent) is the one on which data have been collected. The concept of “migrant” ultimately selected therefore refers to persons living in a country other than their country of origin<sup>10</sup>.

This group was formed to study the following questions: Given the existence of problems such as uprooting, cultural differences, obstacles to keeping families together, etc., are migrants or members of ethnic minorities potentially exposed to the risk of HIV infection? This risk could be associated with the following:

- difficulty of access to information and care,
- difficulty in understanding prevention messages and of adapting these messages to the realities of their own lives (for instance, different approaches to sexuality and to relations between the sexes),
- a particular life-situation (e.g., forced celibacy due to being separated from the family may result in casual sexual relationships),
- difficult financial and social situation (which, for instance, promotes clandestine prostitution, drug abuse, etc.).

The group was set up with the following major aims:

- to collect data on AIDS-related knowledge, attitudes and behaviour and on HIV/AIDS prevention programmes directed at migrants or travellers at national, regional and local levels in European countries (including the description of problems encountered).

- to establish a network among officials and professionals working in the field of migration and HIV/AIDS.

- to propose guidelines and recommendations for preventive action among the most important migrant groups or target groups of travellers, including proposals for future collaborative studies in Europe.

The rationale of the measures and programmes aimed specifically at migrants appears to have varied. They range from integration (i.e. ensuring that information and care are accessible to all), selection (checking of all or part of the migrant population immediately on arrival in the country in order to "protect" the indigenous population), and categorization (consideration of all or part of the migrant population as being inherently "at risk").

In the information field, most European countries have prepared information material or taken special measures aimed at migrants. The nature of these programmes varies considerably: some are organized by the government, some by non-governmental agencies and others by the migrant populations themselves. They show great diversity of both form and content, and, at the very least, include translations of the information material (at least in the early stages when the epidemic was recognized as such) or social-cultural adaptation of the material and of the channels selected for its dissemination. The biggest and earliest efforts have been made by the countries of Northern Europe, which have long-established immigrant populations.

Evaluation in this field is still in the teething stage, often because of lack of funding. One of the CA's main achievements has been to stimulate the development of prevention projects which will have a better chance of being evaluated.

Two points have been given particular attention within the group<sup>11</sup>:

- In view of the difficulties associated with defining numerators and denominators, epidemiological data on incidence or prevalence of AIDS or HIV infection in populations of "foreigners" are very difficult to interpret and, in particular, to compare with those concerning the "native" population or those stemming from other countries. For the numerator, it is primarily the quality of the report that matters (countries may vary as a result of differences in screening policies or in availability of care or differences within the country between migrant and the indigenous population). The denominator problems are even more important since the definition of "foreigner" - for quite diverse practical reasons to do with assimilation and naturalization - varies very greatly from country to country. The criterion of "belonging to an ethnic minority" that is sometimes used is also unsatisfactory for it does not take account of the existence of several generations of migrants with varying degrees of integration.

- The problem of group stigmatization and discrimination against a backdrop of growing xenophobia in a large number of countries confers an element of "gravity" on any research concerning migrants, which calls for a prudent approach and a high level of communication between researchers and the population being investigated.

Use of epidemiological data on (STD) for monitoring the effectiveness of AIDS prevention programmes

The aim of this working group was:

- to consider if it is relevant to use data on STD surveillance to assess AIDS prevention programmes.
- to consider (if relevant) how surveillance of STD in EC/COST

countries could be strengthened so as to monitor change in sexual behaviour and/or HIV sexual transmission.

When a fall in the incidence of sexually transmitted diseases (particularly syphilis and gonorrhoea) in males was registered in several countries in the late 1980s, it was evident that the fall was due to a reduction in high-risk behaviour among homosexual men aimed at avoiding HIV infection. By extension, there was a temptation to draw a parallel between any change in the incidence of STD and the incidence of HIV infection. In the same period, however, the incidence of other STD (HSV, HPV) was on the increase<sup>12</sup>.

Renton and Whitaker<sup>13</sup> reviewed the relevant literature to investigate the theoretical and empirical basis for using STD incidence as a direct indicator of HIV transmission. In particular, they tried to establish which disease(s) was (were) suitable for this purpose. They concluded that the nature of the classic STDs was too different from that of AIDS to be appropriate candidates. They do, however, consider that the epidemiology of sexually transmitted diseases is very useful as an indirect indicator that is linked more to sexual behaviour. They proposed that research should be directed towards achieving a better understanding of the relation between the incidence of STD and any change in sexual behaviour (e.g. establishing which disease is the most sensitive indicator of change in sexual behaviour within a particular population group and what the limits are to any interpretation of such a change).

The final report of this group also provided a description and an analysis of existing STD surveillance systems and relevant data coming from these systems, as well as guidelines for establishing or strengthening STD surveillance in

order to make it appropriate for assessment of sexual behaviour of individuals seeking treatment of a sexually transmitted disease.

### Evaluation problems

The need to evaluate AIDS prevention strategies and the specific measures taken has been generally recognized<sup>14-16</sup> and methodological criteria have been proposed<sup>17,18</sup>. However, though the classic evaluation methods employing control groups have been used for evaluating specific measures, it has not been possible to apply these methods to the evaluation of programmes aimed at large population groups with poorly definable limits (drug abusers, for instance) or to the evaluation of national action strategies. The main obstacle was that it was felt impossible to deprive whole population groups of information regarding a major epidemic. Furthermore, as in other primary preventive campaigns based on information, it is difficult to avoid the problems of contamination of the data of one programme by that of others, given the multiplicity and overlapping of the different sources of information.

This problem makes it also difficult to estimate the causality relationship even in evaluation using control groups. Cross-border comparisons encounter the same difficulties. Europe does not offer the condition of a "natural" experiment: all countries have undertaken prevention activities. Their form and intensity have certainly differed, but the available data are currently insufficient to provide a set of process variables and, more particularly, variables that will make it possible to describe the environment (cultural, political, social and health-related) in which the preventive measures have been applied<sup>19,20</sup>. Therefore a strict comparative evaluation of the strate-

gies is not (yet) feasible. However, it is possible to pinpoint elements in the response to the question "Does prevention yield positive results?" On the other hand, the fact that evaluation activities have been unequally distributed introduces an element of bias into the information. It can be assumed that evaluation activities have been proportional to the intensity of the prevention efforts and will reflect the degree of priority given to AIDS by the different countries concerned.

Through cross-border comparison of data deriving from studies which employ differing methods in order to investigate common areas (particular population groups), however, convergence has been seen at certain levels and the development of common evaluation instruments has been stimulated. Such comparison has shown that the use of complementary approaches (employment of qualitative and quantitative methods, combination of evaluation of both the process and the outcome, for instance) was a valuable contribution to the interpretation of results at the national and international level and represented a novel response to the problem of the difficult of using experimental methods. Finally, it showed that different evaluation strategies could be used to obtain the relevant information for arriving at an understanding of the current situation and for developing future activities, and that tailoring of the evaluation to the needs of the local situation is a key element in selecting strategies. This also suggests that common evaluation strategies may not be all that desirable (they will lose out as far as local usefulness and innovative power are concerned) and that any efforts at standardization must be focused on specific elements (core questions, comparable sampling methods, etc.) related to precise prevention strategies (similar target groups, similar measures).

### What have we learnt that is useful for prevention from the CA?

The agreement of the results obtained shows that behaviour has changed, that such changes can be seen in entire populations, and this has occurred within a very short period of time and in conditions in which information and an appeal to the individual's personal responsibility has largely prevailed over all forms of coercion.

These changes have been more marked in those segments of the population that are most exposed to infection as a result of their behaviour. Talk of prevention has not stirred up widespread fear or rejection reactions on a large scale. Of course, not all the results obtained can be attributed to prevention activities: a certain inherent fear of AIDS, as a result of proximity or acquired after a minimum of information, has probably made its own, separate contribution to the results. Likewise, the effects of social desirability in the responses obtained cannot be ruled out, despite validation efforts. Conversely, in the majority of countries investigated, there is a particular lack of baseline data (i.e. data obtained in advance of any information or measure) on sexual behaviour, which means that the scale of any changes are often underestimated. Another EC Concerted Action<sup>21</sup> has been set up so as to stimulate research in this area.

This is not the time to modify the current preventive strategies, based as they are on broad information of the public in a climate characterized by open-mindedness and voluntary observance of preventive patterns of behaviour. At least in Europe, prevention activities have not been a failure, contrary to what one can sometimes read in the press<sup>22</sup>. It is certainly impossible to know at the present time whether the progress made up to now is sufficient to bring about a lasting change in the evolution of

the epidemic, even though stabilization of infection rates in certain population groups tend to support this view. It has to be borne in mind that currently there is not reasonable alternative to prevention through behavioural changes<sup>23,24</sup>. More particularly, historical examples of prevention efforts (e.g., prevention of smoking or of dental decay) suggest that the progress that can reasonably be expected in a few years is modest; it sometimes takes decades to bring about, and observe, lasting changes. Perseverance in the same direction is therefore required.

Some recommendation on prevention and evaluation can, however, be formulated.

Regarding prevention, there should be not relaxation of efforts, especially since the data obtained show that progress in the adoption of preventive behaviour is flagging. In addition, political differences are emerging on the need to maintain prevention budgets at the current approved level in an environment marked by intense competition to obtain a share of dwindling public funds. Simply to maintain what has already been achieved in term of behavioural change will require substantial long-term investment.

Both continuity of policies and the social consensus which can be created around these policies will clearly be essential for success. The durability of prevention efforts will have to be safeguarded by giving them a firm social anchor (for instance by inclusion in school curricula). In addition, preventive activities will have to be taken over by teams that are closer to the individuals concerned so that the necessary changes in lifestyle can be addressed on a basis that is more effectively tailored to individual needs.

The problems posed by consistent application of effective prevention programmes will also have to be tackled in a more energetic and dif-

ferentiated fashion. As far as prevention of sexual transmission of HIV is concerned, it is no longer enough simply to propagate the use of condoms and the practice of mutual fidelity. Relational skills which enable people to cope with the exigencies of prevention, including the inevitable failures (isolated or recurrent, with or without consequences, etc.) will have to be developed. Seropositivity and the problems it causes will have to be taken more seriously, and particular attention will have to be paid to the increased risk of stigmatization which may occur if preventive behaviour acquires the status of a "social norm". With regard to prevention activities among drug abusers, simply promoting the non-exchange of injection equipment and establishing syringe exchange programmes will no longer be enough. Steps will have to be taken to ensure that what is offered (sterile equipment, substitution or withdrawal treatment) is not only tailored to the actual needs of the population groups exposed but also reaches them.

Regarding evaluation, the value of employing indicators of behaviour and intervention processes and of using complementary methods in research, and the need to establish networks of researchers and to provide standardized research instruments is to be stressed. There is a need for on-going evaluation, the most effective instrument for monitoring progress in prevention activities. Particular stress should be put on observing the development of programmes and the adoption of preventive behaviour among the young.

Researchers are responsible in setting up evaluation programmes which will provide those who design the prevention activities with answers to their questions, and, above all, responsible in ensuring that the results of their research are communicated to all the groups involved (politicians, public

health authorities, prevention workers at all levels, the population as a whole). Only this extended process of dissemination of research findings can provide a guarantee of appropriate choices for those engaged in the continued struggle to combat AIDS.

## Zusammenfassung

### **Evaluation der Prävention von HIV/AIDS: Was haben wir in Europa gelernt?**

Zwischen 1989 und 1992 wurde eine konzertierte Aktion der europäischen Gemeinschaft zur Evaluation von HIV/AIDS durchgeführt. Ihr Ziel war es, die wichtigsten Forscher in diesem Gebiet zu vereinen, eine erste Bewertung der Resultate der AIDS-Prävention durchzuführen und eine Methode zur Evaluation zu entwickeln. Fünf Forschungsbereiche wurden festgelegt:

- Gesamtbevölkerung
- Männer, die sexuelle Beziehungen mit anderen Männern haben
- intravenöse Drogenkonsumierende
- Migranten
- das Monitoring sexuell übertragbarer Krankheiten zur Bestimmung von Veränderungen in sexuellen Verhalten.

Für jeden dieser Bereiche wurde eine Arbeitsgruppe gebildet, die von der Projektleitung und der Koordinationsgruppe beauftragt wurde, Daten über Präventionsprojekte und ihre Evaluation in den verschiedenen europäischen Ländern zu sammeln und zu analysieren. Dieser Überblick stellt die wichtigsten Resultate der konzertierten Aktion vor und zieht einige Schlüsse:

## Résumé

### **Evaluation de la prévention du VIH/SIDA: qu'avons-nous appris en Europe?**

Entre 1989 et 1992 a été conduite une action concertée de la Communauté Européenne sur l'évaluation des stratégies de prévention du VIH/SIDA. Le but de cette entreprise était de: réunir les principaux chercheurs dans ce domaine, faire une première appréciation des résultats de la prévention du sida et de développer une méthode d'évaluation. Cinq domaines d'étude ont été identifiés:

- la population dans son ensemble («population générale»)
- les hommes qui ont des relations sexuelles avec d'autres hommes
- les consommateurs de drogue par injection
- les migrants
- le monitoring des maladies sexuellement transmises pour la détermination des changements de comportements.

Pour chacun de ces domaines, un groupe de travail fut constitué et chargé par la direction du projet et l'équipe de coordination de collecter et d'analyser les données sur les efforts de prévention entrepris et leur évaluation dans les différents pays européens. Cette revue présente les principaux résultats de l'action concertée et en tire les conclusions.

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