

Council of Europe, Committee of Ministers, Recommendation No. R (89) 14 on the Ethical Issues of HIV Infection in the Health Care and Social Settings (Oct. 24,1989), reprinted in 41 International Digest of Health Legislation 39 (1990).

The Committee of Ministers under the terms of Article 15.b of the Statute of the Council of Europe,

Considering that the aim of the Council of Europe is to achieve greater unity between its members and that this aim may be pursued, inter alia, by the adoption of common action in the health field;

Aware of the magnitude of the challenge HIV infection represents for Public Health Authorities in the absence of vaccine and curative treatment;

Conscious in particular of the ethical issues arising in health care and social settings deriving from the need to balance individual and collective rights and duties in the fight against infection;

Believing that respect for the human and social rights of HIV infected individuals and patients with Aids is crucial for the success of a preventive public health policy;

Bearing in mind in this respect the European Convention for the Protection of Human Rights and Fundamental Freedoms, and the European Social Charter;

Recalling its Recommendation No R (87) 25 concerning a Common European Public Health Policy to fight the Acquired Immunodeficiency Syndrome (AIDS) and in particular the recommendations concerning the implementation for a comprehensive information strategy,

Recommends that the Governments of Member States:

- ensure that the principles contained in the Appendix to the Recommendation, drawn up in the light of present knowledge, are reflected in the application of national public health policies to fight HIV infection,

- for this purpose, ensure that the Recommendation is brought to the attention

of all those individuals and bodies responsible for the drawing up and implementation of policies to fight HIV infection.

APPENDIX TO RECOMMENDATION No R (89) 14

I. PUBLIC HEALTH POLICY

In this connection, the three main ethical and legal issues to be addressed are:

- whether to introduce voluntary testing, or various forms of screening;
- whether to offer infected persons the same guarantees of confidentiality, as other patients;
- whether to introduce restrictive measures.

In the light of present knowledge, voluntary testing, integrated into the process of counselling, is the approach which is most effective from the public health point of view, and most acceptable ethically and legally, provided that it is supported by vigorous information campaigns, full respect for confidentiality and the implementation of a non-discriminatory policy.

A. Voluntary testing and screening

It follows from the above that public health authorities are recommended to:

a) in relation to counselling and voluntary testing

- ensure that voluntary testing is easily accessible at sites such as STD clinics, primary health care services, in particular general practitioners' practices, as well as drug treatment centres; that such services respect confidentiality, are always accompanied by counselling and are free of charge (or covered by social security through a confidential system);
- provide training for counselling allowing for the acquisition of the necessary skills by large numbers of health care and social workers especially at primary health care level and by health care volunteers;
- ensure that counselling services are consensual and confidential, provide for continuing psychological and practical support, are respectful of the dignity and autonomy of individuals and assist them in understanding their rights and responsibilities in relation to HIV infection;

- promote and regularly evaluate information and education strategies for the general public and those likely to engage in risk behaviour and promote research on behaviour and attitudes associated with HIV transmission, factors favouring behaviour change and its maintenance;
- intensify targetted health information and education programmes for those who are potentially exposed, stressing the importance of risk behaviours;
- ensure that those population groups most difficult to reach (eg. ethnic minority groups, the sensorily deprived, those with learning difficulties, etc.) are effectively informed through targetted outreach campaigns;
- consider seriously non-coercive pragmatic approaches (eg. the availability of sterile syringes and needles for drug misusers, the provision of instructions on methods of cleaning needles and the availability of condoms in prison), to reduce probabilities of transmission in relation to high-risk situations; such measures should be part of a comprehensive preventive policy including information, counselling and treatment;
- promote the adoption of non-discriminatory policies in all settings concerned and ensure their implementation (see below under V).

b) In relation to systematically offered screening

- carefully examine the advisability of introducing systematically offered screening programmes as a preventive measure in the light of various issues, namely :
 - . the rationale of the proposed programme,
 - . the population to be screened,
 - . specific prevalence rates,
 - . the test method to be used,
 - . the intended use of data obtained from screening,
 - . how results are to be communicated to the person tested and how pre- and post-test counselling is to be accomplished,
 - . the social impact of screening,
 - . legal and ethical considerations raised by the proposed screening programme.

- delegate to health care staff the task of identifying, in the light of specific prevalence rates, groups and individuals to whom targeted testing should be offered, respecting informed consent and confidentiality of data;

- ensure that in order to fulfil the preventive objective of systematically offered screening programmes, counselling services are offered to all individuals to be screened.

c) In relation to systematic screening (routine)

- in the light of present knowledge and in the absence of curative treatment, consider systematic screening unethical and contrary to the rights of individuals, if carried out automatically on population groups without informed consent and without counselling, because it overrides the principles of autonomy and physical integrity, affects the privacy of the individual, and is likely to have serious psychological, social and financial consequences for the individual;

- ensure that such procedures are not carried out by drawing the attention of health care staff and services on ethical unacceptability of these measures.

d) In relation to mandatory screening

- fully implement mandatory screening in respect of donations of blood, and those donating mothers' milk, organs, tissues, cells and semen donation in compliance with the usual strict requirements of informed consent and regulations for confidentiality of data;

- carefully examine how results are to be communicated to the person tested and how pre- and post- test counselling is to be accomplished.

e) In relation to compulsory screening

- consider, in the absence of curative treatment and in view of the impossibility of imposing behaviour modification and the impracticability of restrictive measures, compulsory screening as being unethical, ineffective, unnecessarily intrusive, discriminatory and counterproductive;

- ensure that compulsory screening is not introduced for any population group and especially for any given population group such as "captive" populations e.g. prisoners, immigrants and military recruits;

- make available information and counselling to such groups.

B. Confidentiality

Public health authorities are recommended to:

- in relation to reporting of cases
- ensure that the reporting of Aids cases and, where required by Health Authorities, of seropositivity is used for epidemiological purposes only and therefore carried out in strict compliance with appropriate confidentiality regulations and in particular that data is transmitted on a non-identifiable basis:
 - . to avoid any possible discriminatory use of sensitive health related data,
 - . to avoid discouraging individuals from seeking voluntary testing,
- In relation to the patient-health care worker relationship
- strongly support respect for confidentiality, if necessary by introducing specific policies, and by promoting educational programmes for health care workers to clarify confidentiality issues in relation to HIV infection.
- In relation to partner notification
- ensure that as a general rule there is no partner notification without the consent of the patient, and consider procedures of consultation in accordance with national codes of medical ethics and regulations for the extreme case where a patient refuses to cooperate in the notification of an unsuspecting third party known to the health care worker;
- ensure that the autonomy and the dignity of the patient is fully respected in this context as well as confidentiality;
- draw the attention of health care staff to the crucial role extensive counselling plays for successful partner notification;
- draw the attention of health care staff to the importance of assisting patients in understanding their responsibility towards partners;
- support partner notification within a comprehensive preventive strategy providing accessible services including confidential provider referral where necessary without patient identification;

C. Health controls

Public health authorities are recommended to:

- refrain from introducing restrictions on freedom of movement through ineffective and costly border procedures, for travellers of all kinds, including migrant workers;
- not to resort to coercive measures such as quarantine and isolation for people infected with HIV or those who have developed Aids.

II. HEALTH CARE WORKERS

The general rules applying to the workplace (see section V.A) also apply to health care settings; additional recommendations are however needed in view of the specific caring duties of health staff and the ethical and legal consequences involved.

A. PREVENTION

a) Education and training

- health care workers should receive appropriate education about the human immunodeficiency virus, about infection by the virus, about its psychological and social implications, and about the prevention of infection; such education should also explain the general ethical and legal issues in relation to HIV-infection including its possible recognition as an occupational disease; this education should be integrated into basic, in-service and further education;

- health care workers directly in contact with patients should in particular be educated in:

- . routine use for all patients of safe-handling techniques and procedures for the control of infection by blood and such body substances that might transmit infectious diseases and HIV in particular,

- . epidemiological trends of HIV infection to assist them identify those persons to whom voluntary testing should be proposed,

- . counselling techniques and methods helping to give the necessary psychological support to the patient,

- . ethical and legal issues in relation to HIV infection,

- pre-hospital emergency care providers should also receive basic as well as continuing education on methods to prevent transmission of infectious diseases.

b) Methods and procedures for the prevention of infection in health care settings

- In order to protect health care workers whose job involves exposure to blood and body fluids, or tissues suspected of being infected, permanent and enforceable standards should be adopted as regards standard operating procedures related to the treatment of blood-borne diseases; emphasis should be laid upon precautions designed to prevent needle-stick injuries, and these should be used routinely for all patients;

- these standards should be elaborated on the basis of an evaluation of the potential exposure of health care professionals to infection, through an examination of their working conditions and the specific tasks which they might encounter (*);

- health care workers should consider all patients as potentially infectious and should adhere rigorously to precautions concerning blood, body fluids and tissues or other control of infection procedures;

- hospitals and other medical facilities should, under the supervision of health authorities, implement a system of control and protective measures (including standard operating procedures); in parallel health staff should receive appropriate training, protective equipment should be made available and adherence to recommended control procedures should be monitored; in case of failure, counselling, education and retraining should be made available.

(*) The following classification of risk-related tasks should be recommended:

- Category I : Requires protective equipment to be worn during the task;

- Category II : The task belonging to Category I might occur unexpectedly, therefore protective equipment should be easily and immediately accessible;

- Category III : Does not require any protective equipment.

c) Medical and psychological support for health care staff

- health authorities or other employers concerned should make available (without cost) to any health care professional who cares for HIV patients and who may be at risk of infection:

. medical counselling as a result of the above-mentioned monitoring,

. psycho-social counselling to cope with the strain which health care professionals caring for HIV infected or AIDS patients may undergo;

- following a known or suspected parenteral accidental exposure to blood, body fluids or tissues, serological testing and counselling should be made available; such a monitoring programme should include strict provisions for the protection of the confidentiality of test results.

B. Health care staff infected with HIV

- should be informed and should seek counselling about potential risks associated with taking care of patients with transmissible infections and about measures to minimise the risk of exposure both for themselves and for their patients;

- should refrain from undertaking any "medical activities" that might create even a minimal risk of transmission to patients; this approach also applies to seropositive health care professionals working independently);

- should be counselled, when appropriate, to seek either job restructuring or reallocation of work (if such possibilities exist) or flexible scheduling;

- should be informed of provisions and procedures allowing for the possible recognition of HIV infection as an occupational disease or accident at work.

C. Duty of health professionals

- all health care workers have an obligation to care for people infected with HIV and AIDS patients; only when employee protection is clearly insufficient (lack of protective equipment, training, etc.) may the health care professional decline to perform tasks involving risk. Therefore :

. a health care worker may not ethically and/or contractually refuse to treat a patient whose condition is within his current realm of competence solely because the patient is seropositive,

. any health care worker who is not able to provide the care and services required by a person with AIDS should refer the patient to those doctors or facilities which are equipped to provide such services; until the referral can be accomplished, the doctor must care for the patient to the best of his/her ability,

. the principle of freedom among doctors to choose whether or not to treat patients has to be implemented in such a way that it does not support discrimination against individuals or groups of patients; it should be consistent with rules governing the doctor-patient relationship;

. a violation of these principles should be reported to the competent authority which will act according to legislation.

III. HEALTH CARE AND SOCIAL ASSISTANCE

Discrimination by health care and social services, public or private, should be considered unethical and the interests of social solidarity, where those of the individual and society converge, should be given priority.

Public health authorities are therefore recommended to:

- in relation to social security
- ensure that health care both in- and out-patient, preventive and therapeutic, is either free of charge or that costs are reimbursed in accordance with existing social security systems;
- in relation to health care services
- ensure full provision without discrimination of a comprehensive range of preventive activities and services such as information, counselling, testing, psychological support;
- offer a full range of health care services, both in- and out- patient, including terminal care, staffed by multidisciplinary teams, so that preference can be given to those services which are considered to correspond best to psychological and social requirements of individuals;
- in relation to social assistance
- ensure the cooperation between social workers and health care workers to help those infected in maintaining an integrated and productive life within the community, and to assist them with psychological, family, social, employment, financial and legal questions;
- promote domiciliary health care and home-help services and the setting-up of self-help groups by supporting voluntary associations;

IV. EPIDEMIOLOGICAL RESEARCH

With a view to their possible contribution to the planning of information and education campaigns as well as health care services, the introduction of epidemiological surveys should be considered as a means of assessing the

incidence and prevalence of the infection. To balance the ethical and legal issues they raise and to meet scientific requirements it is recommended that:

- before authorising epidemiological studies of seroprevalence on representative samples of the population, authorities should :

- . ensure that such studies are carried out in compliance with ethical and legal requirements,

- . assess carefully the scientific value of the prospective results in terms of public health strategies;

- if such studies are authorised, the public should be adequately informed;

- if national legislation or regulations allow for testing to be carried out without consent, results should be unlinked and consequently anonymous;

- if testing is to be carried out with consent, linked testing should be done on those who accept and an unlinked test should be offered to those refusing a named testing;

- counselling and voluntary testing should as much as possible be made easily available in settings where unlinked testing is carried out;

V. SOCIAL SETTINGS

As HIV is not transmitted through normal social contact, because of its long latency period and because there is no evidence that HIV infection implies by itself impaired occupational performance, there is no justification for screening for evidence for HIV infection in the workplace nor in educational settings. Similarly discrimination in relation to accommodation cannot be justified.

A. Employment

It is recommended that competent authorities ensure that:

- before employment

- any practice by public or private employers to compel a prospective employee to submit to a test for evidence of HIV infection should be vigorously opposed; the prospective employee should not be subjected to pressure to disclose whether he/she is infected with HIV;

- no sanction should be imposed subsequently if evidence later emerges of an HIV positive test prior to recruitment.

- During employment

- employees should not be compelled to undergo screening for evidence for HIV infection nor to reveal detailed information about personal behaviour;

- employers should see to it that their staff management policies provide HIV infected employees with the same rights and benefits offered to employees with other predispositions, illnesses and disabilities;

- employees with any disease or disability, including HIV infection, should be treated fairly and with understanding and should be allowed to continue working as long as they are able to do so.

- In relation to occupational health services

- occupational health care staff should on no account be compelled by an employer to carry out HIV screening on applicants or employees;

- occupational health care staff if informed by an employee of a possible HIV infection, should treat the employee's case with the usual rules of confidentiality and use such information only in the interest of the patient's health;

- on no account should the occupational health care staff reassess his aptitude in the light of such information (unless the employee might risk exposure to factors in the workplace potentially detrimental to his health), on no account should they be required to inform the employer of the condition of any worker who is HIV infected;

- employers should have a duty to protect the confidentiality of medical information relating to their employees, particularly as concerns HIV infection; therefore health data should only be handled and stored by authorised personnel who are bound by rules on medical confidentiality.

- In relation to staff management policies and information programmes

- employers, top level management and trade union leadership should openly and unequivocally adopt non-discriminatory employment policies and initiate, support and finance educational programmes about HIV infection, its transmission and preventive measures;

- the occupational health doctor should cooperate closely in the development of such programmes.

B. Education

It is recommended that competent authorities ensure that:

- in relation to screening
 - compulsory screening programmes should not be introduced for pupils, students and teachers as a selection procedure;
 - in relation to staff management policies;
 - all recommendations listed under employment should be followed with respect to teachers;

- in relation to information programmes;
 - school health education programmes about HIV-infection and Aids should be an integral part of a more planned and sequential programme of comprehensive school health education which includes education for family life and sex education; they should start before pupils reach the age of puberty;
 - a vigorous training programme should be initiated for teachers and health educators involved;
 - such programmes should be developed in close cooperation with school health services and health care staff in the community to ensure consistency of information and appropriate follow up by health care staff (eg. counselling, testing);

- in relation to confidentiality
 - school health staff, teachers and other educational staff should all strictly respect the principles of confidentiality;
 - decisions on whether to inform the school of the presence of an HIV infected child or adolescent should be taken only when in the interest of the person in question on a case by case basis and after a consultation among, if possible the infected person, the parents, the teachers and the health care staff.

C. Housing

It is recommended that competent authorities:

- contact housing agencies to provide them with information on HIV infection, on the social rights of individuals, on sanctions in case of discriminatory policies;

- promote the organisation of suitable housing arrangements integrated within the community for people infected with HIV in need of accomodation.

VI. INSURANCE

National authorities should cooperate with private insurance companies to elaborate a code of practice with a view to ensuring:

- respect for the dignity and private life of an individual, - seeking of informed consent with counselling for any form of testing, - no introduction of screening for group insurance policies, - protection of health related data and any other confidential information affecting the privacy of the individual, - the adoption of unequivocal policies concerning HIV infection.

National authorities should consider studying insurance possibilities for HIV infected individuals.

In all the settings and situations where discrimination and violation of civil and social rights of an individual may arise, there should be an appropriate and confidential system providing speedy redressement of violation or discrimination.