



Opening up the HIV/AIDS epidemic

Guidance on encouraging beneficial disclosure,
ethical partner counselling and appropriate
use of HIV case-reporting

Executive Summary



Joint United Nations Programme on HIV/AIDS
UNAIDS
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**World Health
Organization**

This document is an executive summary of
Opening up the HIV/AIDS epidemic :
Guidance on encouraging beneficial disclosure, ethical partner
counselling & appropriate use of HIV case-reporting
(UNAIDS Best Practice Collection, Key Material),
copies of which may be obtained from the UNAIDS Information Centre
(also available in other languages)
or accessed directly on the Web site - see below.

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Executive Summary

Faced with the increasingly devastating impact of HIV/AIDS on individual and community well-being, and on development, life expectancy and childhood mortality, many governments have been reviewing the nature of their response to HIV/AIDS. Some have raised the issue of whether the principles of *confidentiality and informed consent* have hindered efforts to prevent the onward transmission of HIV. Particular concern has been expressed regarding the vulnerability of women to infection by husbands or partners who do not know their status, or refuse to reveal it or refuse to practise safe sex. This has led to calls to adopt policies such as named HIV case-reporting, mandatory disclosure of status and criminalizing the deliberate transmission of HIV.

Recent international consultations on these matters have confirmed that the principles of confidentiality and informed consent are *not* obstacles to effective prevention and care programmes. In fact, if employed appropriately, they are not only valid ethical principles, but are also pragmatic tools by which to best protect both the non-infected and the infected. Rather, it is HIV-related *denial, stigma and discrimination*, and the *secrecy* that results from these, that compose major impediments to an effective response to HIV/AIDS.

Although the epidemic is over 15 years old and although HIV prevalence is very high in many communities, HIV/AIDS continues to be *denied* at the national, social and individual levels; to be highly *stigmatized*; and to cause serious *discrimination* based on HIV/AIDS status. There are many reasons for the stigma, denial, discrimination and secrecy that surround HIV/AIDS, and these will differ from culture to culture. However, in general, it can be pointed out that HIV/AIDS is a condition related to sex, blood, death, disease and behaviour which may be illegal – commercial sex, homosexuality, injecting drugs. The fear and taboos associated with these subjects lead to the denial, stigma and discrimination that surround HIV/AIDS, and breed the secrecy that hinders private and community discussion about the issues and behaviour involved.

Denial causes individuals to refuse to acknowledge that they are threatened by a previously unknown virus which requires them to talk about, and to change, intimate behaviour, possibly for the rest of their lives. Denial also causes communities and nations to refuse to acknowledge the HIV threat, and the fact that its causes and consequences will require them to deal with many difficult and controversial subjects, e.g. the nature of cultural norms governing male and female sexuality, the social and economic status of women, sex work, families separated by migration/work, inequities in health care and education, injecting drug use. Stigma and discrimination, and the fact that for many there is no available treatment, cause individuals to fear getting tested for HIV and to fear disclosing it to health care

workers, for care; to families and communities, for support; and to sexual and drug-injecting partners, to prevent onward transmission of HIV.

The prevalence of denial, stigma, discrimination and secrecy indicate that there is a clear and urgent need to “*open up*” the epidemic. How to achieve this? It is neither feasible nor desirable to force people: to get tested (and retested throughout their lives); to disclose their status; to change their behaviour. This would require the creation of a health “police” state requiring vast amounts of resources for testing and policing. It would also drive further underground the very kinds of behaviour that are already hidden and need to be changed.

However, it is feasible and desirable to *open up* the epidemic in ways that will reduce denial, stigma and discrimination, and will create an environment in which many more people have incentives to access prevention and care services, and are supported to change their behaviour for prevention purposes, to disclose their status to partners and families, and receive care, support and compassion. In this document,¹ the UNAIDS Secretariat and WHO offer guidance concerning how this might best be achieved by policies and programmes that encourage:

- **beneficial disclosure;**
- **ethical partner counselling;**
- **appropriate use of HIV case-reporting.**

¹ *Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case-reporting* (UNAIDS Best Practice Collection, Key Material, UNAIDS/WHO, Geneva, November 2000).

As UN system organizations, UNAIDS and WHO are committed to the promotion and protection of human rights, ethical principles and public health. The guidance offered here is based on the firm belief that human rights and ethical principles provide a framework by which the dignity and health of *both* those uninfected and those infected by HIV are safeguarded. Furthermore, adherence to human rights and ethical principles is essential to create an effective public health environment in which the most people are encouraged to, and indeed do, change their behaviour, prevent their own infection or onward transmission, and receive care. Finally, UNAIDS and WHO are also committed to the view that individuals and communities can be, and should be, empowered to deal with the health challenges they face.

In the context of HIV/AIDS, UNAIDS and WHO encourage **beneficial disclosure** of HIV/AIDS status. This is disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for the individual, his/her sexual and drug-injecting partners, and family; leads to greater openness in the community about HIV/AIDS; and meets ethical imperatives so as to maximize good for both the uninfected and the infected.

In order to encourage beneficial disclosure, there should be created an environment in which more people are willing and able to get tested for HIV, and are empowered and encouraged

to change their behaviour according to the results. This can be done by: establishing more voluntary counselling and testing services; providing incentives to get tested in the form of greater access to community care and support, and examples of positive living; and removing disincentives to testing and disclosure by protecting people from stigma and discrimination.

There already exist a number of community care and support programmes throughout the world that are achieving these results. These should be replicated within and outside governmental programmes. Further, much more can be done by governments to encourage voluntary testing, counselling and beneficial disclosure by implementing public information and media campaigns that promote tolerance and compassion; enacting laws and regulations and implementing legal and social support services that protect against discrimination; supporting community-based organizations engaged in these activities; and involving people living with HIV/AIDS in the formulation and implementation of HIV programmes and policies.

With regard to partner counselling (partner notification), UNAIDS and WHO encourage **ethical partner counselling**. Such partner counselling is based on the informed consent of the source client, and maintains the confidentiality of the source client, where possible. However, it also takes into account the serious possible consequence of not counselling partners – that is, HIV infection.

Because refusal to counsel partners can result in the onward transmission of HIV, HIV counselling and partner counselling programmes should involve strong and professional efforts to encourage, persuade and support HIV-positive persons to notify and counsel partners. In the few cases in which a properly counselled HIV-positive person refuses to counsel partners, the health care provider should be able to counsel partners, without the consent of the source client, after there has been an ethical weighing of the potential harms involved, and appropriate steps have been taken. These steps involve repeated efforts to persuade the source client to counsel partners, informing the source client that partner counselling will occur, keeping his/her name confidential if possible; and ensuring social and legal support for the source client and other relevant parties (spouses, partners, family members) to protect them from any physical abuse, discrimination and stigma which may result from partner counselling.

There is much that governments can do to create conditions to encourage ethical partner counselling. These include setting out policies, laws and guidelines which protect confidentiality and informed consent, and outline clearly the limited circumstances under which partner counselling may take place without consent; training health care workers and counsellors in ethical partner counselling; and increasing social and legal support for those who are involved in partner counselling.

UNAIDS and WHO recommend the **appropriate use of HIV case-reporting**. It has been suggested that HIV case-reporting, including named HIV case-reporting (i.e. the reporting to public health authorities of each individual identified as HIV-positive) could provide accurate information on the spread of HIV, and allow effective actions to prevent further infections and ensure access to care services. However, in resource-poor settings, certain conditions result in the fact that HIV case-reporting does not provide accurate data for surveillance purposes and does not result in better prevention and care. These conditions are: little access to, or use of, HIV tests; a reporting system which suffers from under-reporting, under-diagnosing and insufficient infrastructure to protect confidentiality; little or no access to anti-retrovirals; and limited resources which would be better utilized in increasing access to voluntary testing and care and improving prevention activities. In countries where such conditions exist, it is recommended that HIV case-reporting *not* be carried out.

Rather, in assessing the use of HIV case-reporting and other surveillance strategies, countries should refer to the framework of **second-generation HIV surveillance**, where UNAIDS and WHO recommend a combination of both biological and behavioural surveillance tools and suggest that a country choose appropriate surveillance based on its resources and the nature of its epidemic burden and health care response. In general, such surveillance is cost-effective given the financial and human

resources available; refines, as well as reinforces, prevention and care efforts; maintains confidentiality; optimizes access to available treatment options, where this is possible; and leads to regular and wide dissemination of information to the population in non-stigmatizing ways that help to open up the epidemic, decrease denial and increase commitment to fight the epidemic. In low-income countries, depending on the state of the epidemic and other factors, it is likely that HIV sentinel surveillance will be the most appropriate form of surveillance to employ.

UNAIDS/WHO

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



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