

Opening up the HIV/AIDS epidemic

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



Joint United Nations Programme on HIV/AIDS

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1

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 hinder 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, 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.**

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.

2

Introduction

HIV/AIDS is an unprecedented epidemic and public health emergency. Presently, worldwide, it is estimated that over 33 million people are infected with HIV, and over 16 million have died of AIDS-related illnesses. In many resource-poor countries and among marginalized groups of people in industrialized countries, the number of new HIV infections continues to rise. In some countries in Africa, AIDS-related morbidity and mortality are causing major reversals in development, childhood mortality, and survival and life expectancy.¹ In light of this, and sometimes with a sense of desperation, many governments and communities are reviewing the effectiveness of their HIV/AIDS programmes. This review has taken place against the backdrop of a deepening realization of the enormous impact that HIV/AIDS is having on the well-being of individuals, families and communities. It evidences a growing political commitment to HIV prevention and care.

In the context of this review, some governments have considered whether the principles of *confidentiality* and *informed consent* contribute to the spread of HIV. There is concern that these principles allow a person who is HIV positive to keep his or her status confidential, and refuse to share it with sexual (or drug-injecting) partners, family members or the community. Governments and others have asked whether these principles hinder efforts to prevent the spread of HIV and deny protection to the sexual and drug-injecting partners of those infected. There is also concern that the principle of confidentiality contributes to the "invisible" status of the epidemic and to the general denial of HIV/AIDS within communities and nations. As a result, policy-makers have begun to consider legislation and practice that would allow breaches in confidentiality, mandatory partner notification and named HIV case-reporting for public health reasons; and would permit the criminal prosecution of individuals who are considered to have spread the virus deliberately.

To address some of the concerns, and in response to a request for WHO assistance made by Ministers of Health in Africa, WHO (AFRO) and the UNAIDS Secretariat cosponsored a regional technical consultation on *notification, confidentiality and HIV/AIDS* in August 1999 in Windhoek, Namibia. A meeting statement was produced that aimed to assist Ministers of Health and other partners in southern Africa to develop policy and guidelines.² Further, in October 1999, the UNAIDS Secretariat and WHO cohosted an international consultation in Geneva, Switzerland, on *HIV reporting and disclosure*. This consultation included epidemiologists, public health officials, national AIDS programme managers, people with HIV/AIDS, lawyers and human rights activists from more than 20 countries.

The Windhoek and Geneva meetings confirmed that the principles of confidentiality and informed consent *do not* contribute to the spread of HIV/AIDS. Indeed, if employed in the appropriate context and in creative and culturally sensitive ways, confidentiality and informed consent can help to decrease the spread of HIV/AIDS.

¹ See *UNAIDS/WHO AIDS Epidemic Update*, December 1999, pp.5, 16 and 17.

² Entitled "Technical Consultation on Notification, Confidentiality and HIV/AIDS, Windhoek, Namibia, 4-6 August 1999, Meeting Statement", available from WHO or UNAIDS, Geneva.

Rather, responsibility lies with the *denial, stigma and discrimination* which continue to surround HIV/AIDS, and which result in a high level of *secrecy* concerning the epidemic. These disempower both individuals and communities in their efforts to cope with HIV/AIDS. This denial, stigma and discrimination, and the resulting secrecy, must be overcome and the HIV/AIDS epidemic “normalized” into what it is – a viral infection, as well as a major human, health and development crisis.

The relevance of ethical principles such as confidentiality and informed consent has been raised throughout the history of the response to the epidemic. That these come under examination again at this stage is a necessary and welcome development. In general, it highlights the need for greater efforts to “*open up*” the HIV/AIDS epidemic. In particular, it highlights the need to identify more clearly the causes and consequences of the *denial, stigma, discrimination and secrecy* that surround HIV/AIDS and hinder effective responses; and the need to identify, fund and implement strategies that will overcome them, and lead to more effective prevention, care and support.

Denial, stigma, discrimination and secrecy regarding HIV/AIDS continue to exist even though prevalence of HIV, and deaths from AIDS, are very high in many places. They stem from several causes. At the individual level, people do not want to acknowledge that HIV/AIDS is within their communities, that it poses a real personal threat to them and to their families, that they themselves may already be infected and that they may be transmitting the virus to their sexual or drug-injecting partners. Furthermore, people do not want to get tested for HIV or to disclose their HIV status because they fear that they will be rejected by their partners, that they will face stigma and discrimination, and/or that they will be blamed for infecting others. Finally, most people in the developing world know they will not have access to drugs and treatment which would slow down the progression of the disease or alleviate its pain and suffering. Thus, denial, stigma, discrimination and lack of access to care stem from, and lead to, a sense of fear and hopelessness, and encourage secrecy about HIV/AIDS.

At the community level, many resource-poor communities are struggling with extremely difficult conditions in which to combat HIV/AIDS. They suffer from insufficient health care and education services, including insufficient voluntary testing and counselling; insufficient public education campaigns, particularly education targeted to young people, women and marginalized groups; insufficient access not only to anti-retroviral drugs but also to drugs to reduce the pain and suffering caused by AIDS-related illnesses; and insufficient community organization and support, including lack of a social and legal infrastructure to protect people from HIV-related discrimination. These conditions are exacerbated among marginalized groups in communities. These obstacles seriously hamper government and community efforts to prevent the spread of HIV and to provide care and support for those affected by HIV/AIDS. They also reinforce the denial, secrecy, stigma and discrimination that exist.

Governments and communities have felt at a loss to know how to combat this denial, stigma, discrimination and secrecy. This has justified calls for “new or different” approaches to respond to the epidemic, particularly in high-prevalence areas. Mandatory HIV case-reporting and disclosure of HIV status, particularly to sexual partners but also to communities, have been suggested as sound public health measures. More generally, discussions have been initiated nationally, regionally and internationally on how to :

- create greater openness about HIV/AIDS among individuals and within families and communities;
- encourage more people to test for HIV, inform sexual partners about the results and prevent further infections;
- better protect people not infected from becoming infected;
- increase acceptance, care and support for people and families affected by HIV/AIDS;
- improve epidemiological surveillance of HIV and AIDS.

This document is a follow-up to the Technical Consultation on Notification, Confidentiality and HIV/AIDS in Windhoek, and the International Consultation on HIV Reporting and Disclosure (Geneva), and draws from the expertise and input made at these meetings in an effort to offer assistance in answering these questions. It proposes that vital and effective steps towards opening up the HIV/AIDS epidemic involve the encouragement of **beneficial disclosure, ethical partner counselling and the appropriate use of HIV case-reporting.**

The UNAIDS Secretariat and WHO offer guidance concerning these issues in a context that involves commitment to human rights, ethical principles, public health and community empowerment. Such a context protects the health and safety of the individual both infected and uninfected; it also protects public health. It does so by creating an environment that encourages the most people to get tested for HIV; encourages people to change their behaviour either to prevent their own infection or that of others and, where infected, to feel able and willing to disclose their status in a way that prevents onward transmission of HIV; and results in care and compassion. Such an environment will help to open up the epidemic; reduce the denial, stigma, discrimination and secrecy surrounding HIV/AIDS; and fashion programmes that allow governments, communities and individuals to deal with the causes and consequences of HIV/AIDS in the most effective and humane ways possible.

Distinguishing between confidentiality and secrecy

It is important at the outset to distinguish between “confidentiality” and “secrecy”. Confidentiality is an ethical principle particularly relevant in the provision of health care.³ The principle of confidentiality encompasses the view that a person should be entitled to privacy with regard to his or her most personal physical and psychological secrets; but it is also the basis for an effective relationship between patient/client and health care provider, and hence the basis for the effectiveness of many public health interventions which rest on these relationships. Only if a person feels sure that the health care provider will keep confidential any information provided will he/she come forward and share information that may be critical to making decisions about effective clinical care and treatment.

³In addition to the doctor/patient relationship and the clinical setting, confidentiality is also an ethical duty in other professional fields, such as social work, psychiatry, psychotherapy and the practice of law, and in research involving human participants.

Thus, health care professionals have long recognized and respected their duty, and the need, to protect the confidentiality of their patients. Because of the need to protect confidentiality in order to provide effective health care, health care professionals also recognize that they should normally only disclose highly personal information, such as HIV status, with the informed consent of the patient.

However, the principle of confidentiality is not absolute, and there are situations where it is not maintained. One of these occurs when necessary and relevant information is shared among health care professionals who are responsible for the clinical management of a person's health needs. Often a small group of professionals, usually in a hospital or clinic setting, will share personal information about a client, including HIV status, which is essential to the effective treatment of the case, but confidentiality will be maintained within this professional group. Another situation where confidentiality may be breached without the consent of the patient occurs when there is a clear indication that a third party may be harmed by the actions of the patient. In these situations the ethical principle of confidentiality may conflict with the ethical principle to "do no harm", and a difficult but necessary ethical weighing of the potential harms and benefits to the parties involved should be undertaken in order to decide how to proceed.⁴ In this paper, there is a full discussion of how such relatively rare cases in the context of HIV/AIDS should be handled.

The ethical principles of confidentiality and informed consent, which have private and public health benefits, should be distinguished from "secrecy" which is a state of affairs often resulting from fear, shame and/or a sense of vulnerability. Whether secrecy is maintained depends solely on the personal motives of those who hold the secret. As discussed above, motives to maintain secrecy in the context of HIV/AIDS involve not only fear and shame, but also denial, and fear of rejection, stigma and discrimination. To the degree that secrecy harms the infected and the uninfected, and undermines an individual's, family's or community's ability to cope positively with HIV/AIDS, it should be strongly combated. UNAIDS and WHO are of the view that the secrecy surrounding HIV/AIDS, and the related stigma, denial and discrimination, can best be countered by a greatly increased commitment to *beneficial disclosure, ethical partner counselling and appropriate use of HIV case-reporting*, as described below.

⁴For more on these issues in the context of HIV, see Jurgens R. *HIV Testing and Confidentiality: Final Report*. Montreal, Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998, pp.209-224; *Confidentiality*, Number 17 of a series of 19 Info Sheets on HIV Testing. Montreal, Canadian HIV/AIDS Legal Network, 2000.

3 Encouraging beneficial disclosure

Overview

“**D**isclosure” is a neutral term. In the context of HIV/AIDS, it refers to the act of informing any individual or organization (e.g. health authority, employer, school) of the HIV status of an infected person, or it refers to the fact that such information has been transmitted, by any means, by the person him or herself, or by a third party, with or without consent (from **Definition of important terms** in Annex 1).⁵

However, the purposes and the consequences of disclosure may be beneficial or harmful. Examples of beneficial disclosure involve instances where an HIV-positive person informs a sexual partner of his/her status for prevention purposes, or informs family, community members or health care workers in order to share vital personal information and obtain support. Or disclosure may involve a health care worker providing information regarding an HIV/AIDS case on a confidential basis to other health care workers involved in the management of the patient; to a health authority for surveillance purposes; or, where necessary, to a partner of an HIV-positive person to prevent onward transmission of HIV (see section below on partner counselling).

Examples of harmful disclosure involve cases where disclosure is made without the consent of the person who is HIV positive and has adverse consequences for that person, such as stigma, abandonment, physical violence, imprisonment, loss of job or housing, or other forms of discrimination. Harmful disclosure may also impair prevention and care activities. Where people fear forced testing, or disclosure involving lack of confidentiality, they will avoid HIV counselling, testing, treatment and support, because these are likely to mean that their HIV status will become known against their will and they will face stigma, discrimination, lack of privacy and other negative effects. Thus, fear of lack of confidentiality and forced disclosure drives people away from HIV services, reducing opportunities to encourage and empower people to change their behaviour in order either to avoid getting infected or to avoid passing on their infection. It may also drive people away from other health care services, such as antenatal care or blood donation.

UNAIDS and WHO encourage **beneficial disclosure**. This is disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for those individuals, *and* for their families and sexual and drug-injecting partners; leads to greater openness in the community about HIV/AIDS; and meets the ethical imperatives of the situation where there is need to prevent onward transmission of HIV.⁶

Such beneficial disclosure, with its elements of voluntariness and confidentiality, not only maintains ethical principles but also serves a direct public health

⁵ From *Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS, Public Health and Human Rights Implications*. Geneva, WHO/UNAIDS, June 1999 (UNAIDS/00.26E).

⁶ For discussion of cases where it may be appropriate to disclose someone's status without their consent in order to prevent onward transmission of HIV, see section on ethical partner counselling at page 18.

function, because it encourages people to access HIV prevention and care services. It does this by establishing a climate of trust between health care providers and those who need HIV services, allaying their fears and respecting them as people who can and will make the right decisions regarding their behaviour. Beneficial disclosure also serves the goal of opening up the HIV/AIDS epidemic. As more people feel able and willing to disclose their status, there grows a critical mass of individuals and families within a community, and indeed within a nation, who are openly involved in dealing with the epidemic in positive and supportive ways. As a consequence, discrimination, stigma and secrecy are reduced.

Nevertheless, preconditions are necessary to promote beneficial disclosure and to encourage people to access prevention and care programmes. People must have access to voluntary counselling and testing (VCT) services in which they can learn their HIV status and receive support and referral in dealing with the news. Furthermore, they must have an incentive to find out their status such that it will mean greater social support, access to health care options and an increased ability to live a rewarding life regardless of a negative or positive status. Finally, they must not fear stigma and discrimination if found to be HIV positive.

Creating incentives to disclose by improving access to voluntary HIV counselling, testing, treatment and care

It is estimated that up to 90% of HIV-positive people in low-income countries do not know their HIV status.⁷ In large part, this is due to the fact that there are few VCT facilities available to the populations most affected by HIV/AIDS. However, even where testing is available, many people do not want to be tested because of a perception that “nothing is to be gained” by knowing an HIV-positive status. For the poor there will be little access to HIV/AIDS treatment and care. Furthermore, there will likely be stigma and discrimination to be faced if found to be HIV positive, as noted above.

However, even in resource-poor settings much can be done to improve access to voluntary counselling, HIV testing, treatment and care, though this may involve a shift of resources from “traditional” HIV programmes and activities. Primarily, there must be greater investment in establishing VCT services in communities. Secondly, incentives must be created to encourage people to undergo testing. These should take the form of community services providing support, treatment and care. Finally, disincentives to test, such as stigma and discrimination, should be removed.

As already noted, there are insufficient VCT services in the communities most in need of them.⁸ More resources from national AIDS programmes should be devoted to establishing such services,⁹ which can take many forms. Most important are

⁷See Zambia sexual behaviour survey 1998. Republic of Zambia, MEASURE and Central Statistical Office, 45; Tyndall et al., Evaluation of AIDS control strategies in women attending a family planning clinic in Nairobi, Kenya, International Conference on AIDS, 1996 (abstract no.We.D.3760).

⁸For more on the availability of VCT, see *Report on the Global HIV/AIDS Epidemic*. Geneva, June 2000 (UNAIDS/00.13E).

⁹See Report of the Meeting on Theme Groups on International Partnership against HIV/AIDS (IPAA) in Africa, Nairobi, 24-27 January 2000, p.8, where there was a call to accelerate operation research on VCT and mother-to-child transmission prevention “in order to make these interventions central in the implementation of the IPAA,” available from UNAIDS, Geneva.

that VCT services are integrated into existing services where applicable (e.g. antenatal care, sexually transmitted infection (STI) clinics, family health clinics); they are user friendly (particularly to youth and women); are accessible to marginalized groups (e.g. the poor, rural populations, sex workers, drug injectors, migrants); and are designed to tie the individual using them into other support and care options (e.g. referral to STI services, support groups, family outreach programmes).¹⁰ The creation and availability of such services is a prerequisite if people are to learn about their HIV status and find ways of dealing with it constructively, including through disclosure.

However, the existence of VCT services is not in itself enough to get people to come forward for HIV testing. There must be incentives, and these should take the form of greater availability and affordability of care, treatment and support. In resource-poor settings, treatment, in the form of drugs, and care options are very limited. However, these obstacles can in part be overcome by innovative and far-reaching community-based programmes. Such programmes offer outreach to affected families, voluntary and confidential counselling and testing, support groups, home visits, follow-up and involvement of people living with HIV/AIDS in prevention and care activities. They may also offer models of how to “live positively” with HIV/AIDS, through which people maximize their personal and social resources, live as best as possible in the present and plan realistically for the future.

Examples of such effective community-based programmes can be found in Uganda, Tanzania and Thailand, where campaigns by non-governmental organizations (NGOs) to encourage testing have created more openness and discussion about HIV.^{11 12 13} In the parts of these countries where HIV testing has been made reasonably accessible to affected communities, the synergistic link between reducing stigma, increasing voluntary testing and encouraging disclosure has been confirmed. Each of these activities reinforces the others and leads to greater numbers of people taking advantage of voluntary counselling, testing and support.^{14 15} This leads to more voluntary disclosure (to spouses, lovers, family members, friends and health care providers), the adoption of low-risk behaviour and a movement towards positive living.^{16 17}

When such programmes are well integrated into the community and are responding to its needs, they can have a profound influence on how HIV/AIDS is perceived at the individual, family and community levels. Positive-living models, as well as the active involvement of people living with and affected by HIV/AIDS, help to change attitudes from stigma and discrimination to respect and support. Affected

¹⁰ See *Voluntary Counselling and Testing Technical Update*. Geneva, UNAIDS, May 2000 (WC 503.6).

¹¹ UNAIDS Case Study, *Knowledge is Power: Voluntary HIV Counselling and Testing in Uganda*. Geneva, June 1999, (UNAIDS/99.8E).

¹² Vollmer N, Valadez J. A psychological epidemiology of people seeking HIV/AIDS counselling in Kenya: an approach for improving counselling training. *AIDS*, 1999, 13:1557-1567.

¹³ Kallidjian L, Jekel J, Friedland G. End-of-life decisions in HIV positive patients: the role of spiritual beliefs. *AIDS*, 1998, 12:103-107.

¹⁴ Meursing K, Sibindi F. Condoms, family planning and living with HIV in Zimbabwe. *Reproductive Health Matters*, 1995, 5:56-62.

¹⁵ Meursing K. *A World of Silence. Living with HIV in Matabeleland, Zimbabwe*. The Netherlands, Royal Tropical Institute, 1997.

¹⁶ Lie G, Biswalo P. Positive patient's choice of a significant other to be informed about the HIV test result: findings from an HIV/AIDS counselling programme in the regional hospitals of Arusha and Kilimanjaro, Tanzania. *AIDS Care*, 1996, 8(3):285-296.

¹⁷ TASO Uganda. *The Inside Story. Participatory evaluation of the HIV/AIDS Counselling, Medical and Social Services 1993-94* (WHO/GPA/TCO/HCS/95.1).

families and communities are able to embrace their situation, are given support in how to best deal with it, while the family member who is HIV positive is still able to contribute to family and community efforts. This helps to reduce the stigma and to change public perceptions of HIV and people living with HIV/AIDS. It also helps to encourage more people who do not know their status to come forward voluntarily for counselling and testing.

Thus, there needs to be greater investment in creating the facilities for HIV testing, as well as in backing community-based programmes which create a supportive environment and encourage people to come forward for HIV testing, counselling, care, treatment and support. Then beneficial disclosure will increase and lead to more prevention (protection of those not yet infected), and more care and support for those already infected.

Removing disincentives to disclose by reducing stigma, discrimination and lack of confidentiality

Despite the fact that millions of people worldwide are infected with HIV, there is still considerable shame, secrecy and fear surrounding HIV; people living with HIV and AIDS are highly stigmatized. HIV is also the cause of human rights violations and acts of discrimination. As a result of the stigma and discrimination surrounding HIV/AIDS, those who *do know* their HIV status are afraid to disclose it because of the risk of job loss, social ostracism, violence and threats to their lives, and other adverse consequences. Those who *do not know* their status are afraid to get tested if they fear that the results will be made known against their will and they will face stigma and discrimination.

Thus, to encourage voluntary testing, beneficial disclosure and use of HIV services, the disincentives of stigma and discrimination, and lack of confidentiality, must be removed. Many steps can be taken to reduce stigma and discrimination. One of the most under-utilized has been public information campaigns which focus *specifically* on the promotion of tolerance, compassion and non-discrimination. Though the world has been inundated with public information about the fact that HIV cannot be transmitted casually, this information has not done enough to alleviate fear of HIV and AIDS and of people living with them. Public information campaigns should be conducted which involve creative, attractive, powerful messages against discrimination and stigma. Public forums on HIV/AIDS and/or community discussion groups, which focus on compassion, tolerance and support, should also be held.

Where there is protection against violence and discrimination, public figures (actors, politicians, athletes), including those living with HIV, should be involved in these public campaigns. The involvement of people living with HIV/AIDS in public campaigns, and in policy, programmatic and community activities, is critical to give a human face to the epidemic, to reaffirm the value of people with HIV/AIDS and to change attitudes of stigma. It also ensures that policies and programmes will be sensitive to the actual needs and realities of those affected by HIV/AIDS.¹⁸

¹⁸ For more on the involvement of people living with HIV/AIDS, see *From Principle to Practice, The Greater Involvement of People Living with HIV/AIDS*. Geneva, 1999 (UNAIDS/99.43E).

Other measures can be undertaken at a national level, such as the enactment of laws and policies against HIV-related discrimination¹⁹ and against breaches in confidentiality and informed consent. One essential step is the training and sensitization of professionals who work with people affected by HIV/AIDS. It is often at the hands of such professionals that people affected by HIV/AIDS suffer the worst discrimination, despite the professional and ethical responsibility to treat people who are HIV positive with dignity and compassion, and to protect their confidentiality in appropriate ways. Key professionals who might benefit from training in non-discrimination, confidentiality and informed consent are health care workers, police, social service providers, lawyers and judges.

Health care workers should be more empowered to handle the medical, as well as psychosocial, management of clients with HIV/AIDS.²⁰ This should include training and empowerment regarding universal precautions against transmission of infectious diseases, as it is the fear of transmission of HIV among health care workers that often leads to stigma and discrimination against people with HIV/AIDS. Experience has shown that the impact of this training in health settings needs regular monitoring and staff updating to ensure that infection control procedures are maintained.²¹

Recommendations for encouraging beneficial disclosure

- Conduct public information campaigns and community forums aimed at promoting tolerance, compassion and understanding, and reducing fear, stigma and discrimination.
- Encourage participation of people living with HIV/AIDS in public information campaigns and in HIV programmes and policy formulation.
- Establish more VCT services, including in rural areas and for marginalized groups.
- Support governmental agencies, NGOs and community-based organizations (CBOs) to make community-based services, including VCT, family outreach, community support, positive living, support groups and care options more widely available.
- Encourage the media to report on HIV/AIDS in a responsible, non-discriminatory and non-sensational manner.²²
- Train health care workers in the management of HIV and universal precautions, in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.

¹⁹ See *Handbook for Legislators on HIV/AIDS*. Geneva, UNAIDS/IPU, 1999 (UNAIDS/99.48E).

²⁰ For examples and more discussion, see Bharat, Shalini, *HIV/AIDS Related Discrimination, Stigmatisation and Denial in India – A study in Mumbai and Bangalore*, 1999, available from UNAIDS, Geneva.

²¹ See Miller, D. *Dying to Care?: Work, Stress and Burnout in HIV/AIDS*. London, Routledge, 2000.

²² Adam G, Harford N. *Radio and HIV/AIDS: Making a Difference. A Guide for Radio Practitioners, Health Workers and Donors*. Geneva, UNAIDS/Media Action International, 1999.

- Train other professionals (social workers, police, lawyers, judges) in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train key personnel in non-health employment settings, including human resource management in industry, in promoting non-discriminatory practices in the workplace.²³
- Enact or reform laws, administrative guidelines and professional codes of conduct to prohibit discrimination and breaches of confidentiality related to HIV status.
- Create legal support services for those who have suffered discrimination based on HIV status.

²³ For an example of this type of activity, see the Intersectoral Committee on AIDS and Employment/OATUU: Labour Relations Regulations on HIV/AIDS and Employment. Zimbabwe, ICAE/OATUU, January 1999 (SI 202 1998).

4 Encouraging ethical partner counselling (partner notification)

Overview

Partner counselling or partner notification²⁴ involves the process of contacting sexual and/or injecting partners of an HIV-positive person (in this context often called the “source” or “index” client or patient) in order to advise these partners that they may have been exposed to HIV and to encourage them to attend for HIV counselling, testing and, where applicable, treatment.²⁵ The objectives of this kind of disclosure are to:

- prevent HIV transmission to people who may be exposed either sexually or through needle-sharing;
- improve care and support for people living with HIV or AIDS.²⁶

Partner counselling can be undertaken by the source client or patient him/herself, by the health care provider or through the combined efforts of both.

Source referral: HIV-positive people are encouraged to counsel partners concerning their possible exposure to HIV. This takes place without the direct involvement of health care providers. In this approach, the health care provider works with the HIV-positive person regarding the nature of the information to be passed on to their partner(s) and ways of doing it.

Provider referral: an HIV-positive person gives the name(s) of his/her partner(s) to a health care provider who then confidentially counsels the partner(s) directly. In this approach, the health care provider does not disclose the name of the HIV-positive person to the partner, but only provides the information that the partner is likely to have been exposed to HIV infection. This is done with the consent of the source client or patient.

Conditional referral: the health care provider of the source client or patient obtains the names of his/her sexual/drug-injecting partner(s), but allows the source client a period of time to counsel the partner(s) him/herself. If partners are not counselled within this time period, the health care

²⁴ The UNAIDS/WHO Consultation on HIV Reporting and Disclosure, Geneva, 20-22 October 1999, recommended that the term “partner counselling” should be substituted for the term “partner notification” because, in some contexts, partner notification is associated with coercion and pressure. The Centers for Disease Control, Atlanta, Georgia, USA, now uses the term “partner counselling”. In this document, the term “partner counselling” will generally be used.

²⁵ See also Bayer R, Fairchild A. *The Role of Name-based Notification in Public Health and Surveillance*. Geneva, 2000 (UNAIDS/0028E).

²⁶ See also “partner counselling” in Annex 1, Definitions of important terms.

provider counsels the partners, without naming the source patient or client concerned. (For more on partner counselling without the consent of the source client, see text below, page 21.)

Partner counselling/notification has a long history as one possible aspect of the public health response to STIs other than HIV, such as syphilis and gonorrhoea. As noted above, there is current debate whether, in the context of the transmission of HIV, the status and/or name of an HIV-positive person should be disclosed **mandatorily** to his or her sexual or drug-injecting partners. This is a particular concern in Africa and Asia where many women are being infected by their husbands or regular partners who do not reveal their HIV status or practise safe sex.

However, in the history of partner counselling, there are no clear data indicating that the mandatory counselling of partners is more effective in preventing transmission than the voluntary counselling of partners. As stated earlier, it does appear that when people think that they will be forced to notify their partners, or that their status will be revealed without their consent, they choose not to attend for STI testing, counselling or other prevention and care services. This has been true in the case of syphilis and gonorrhoea even though, unlike HIV, these are curable and attract much less stigma and discrimination than HIV/AIDS. It is even more likely that a policy of mandatory partner counselling will deter people from using HIV testing and counselling services, because there is greater incentive to fear testing and disclosure because of the serious stigma and discrimination surrounding HIV/AIDS.²⁷

In fact, the reality is that, in many hospitals and clinics in low-income countries, disclosure of HIV status to sexual partners and others, such as family members, often takes place without consent. This happens because there are insufficient resources and personnel to store information in a way that respects privacy and/or because health care providers do not understand the professional duties of confidentiality and informed consent and their importance in the management of HIV/AIDS. This failure of health authorities to protect the privacy and autonomy of patients deters many people in these countries from seeking HIV counselling, testing and care.

Furthermore, it is not possible or practical to implement a large-scale scheme of mandatory partner counselling. It is virtually impossible to force people to test mandatorily for HIV, to retest periodically and to continue to inform partners, as would be necessary. Nor do people always know, or remember, the names of their sexual partners. Nor is it possible to force them to reveal them. Finally, it is very costly to train and employ staff to trace and counsel all those whose names are given.

Most important, however, it appears that mandatory partner counselling schemes are not necessary because *voluntary* partner counselling schemes can accomplish the critical goals. Voluntary partner counselling schemes can help to create a climate of confidence which will attract people to HIV testing and counselling services so that more people learn of their HIV status. Among those who do attend health care facilities and are faced with a decision whether to notify partners or not, it appears that *most* people *agree* to do so, on a voluntary basis, after counselling. In the context of a generally voluntary partner counselling programme, the small number

²⁷ See also Rothenberg RB, Pterate JJ. Partner notification for sexually transmitted disease and HIV infection, in *Sexually Transmitted Disease*, 3rd edition, NY, McGraw-Hill, 1999; Nuwaha et al., Psychosocial determinants for sexual partner referral in Uganda, qualitative results. *International Journal of STD and AIDS*, 2000, 11:156-161.

of cases where persons refuse to notify their partners can be taken care of on an individual basis, as described below.

Thus, for reasons of principle and because it is more feasible and capable of success, UNAIDS and WHO encourage **ethical partner counselling**. Ethical partner counselling is based on the informed consent of the source client or patient and, where possible, maintains the confidentiality of the source client or patient: that is, his/her name is not revealed to the partners being counselled. This will often be extremely difficult to maintain in the context of marital relationships, and requires the provision of counselling and support to both spouses to ensure the prospect of abuse and discrimination is minimized or eliminated. Ethical partner counselling also takes into account the serious consequence of *not* counselling partners – possible HIV infection. This consequence requires an ethical weighing of the benefits and harm that are likely to occur if and when there is refusal on the part of an HIV-positive person to counsel partners.

In light of this, UNAIDS and WHO encourage ethical partner counselling programmes which:

- employ serious counselling and persuasion towards counselling of partners;
- empower the health care provider, when the source client refuses to notify his/her partner, to make ethical decisions based on the potential harm and benefits to the parties, and decide whether to counsel the partner(s) without the consent of the source client, in the circumstances outlined below;
- provide social and legal support for the source client and other relevant parties (spouses, partners, family members) to protect them from physical abuse, discrimination and stigma which may result from partner counselling.

Furthermore, UNAIDS and WHO advocate that there be greater exploration of concepts and practices concerning partner counselling which are culturally appropriate, ethically sound and effective in achieving prevention and care goals. One example is the concept of **“shared confidentiality”**. In Uganda and some other African countries, this notion of shared confidentiality has been developed by communities, NGOs and health care providers. A person affected by HIV is encouraged, and voluntarily chooses, to disclose his/her status to a range of people from whom s/he can get support. In the words of a former counsellor from Uganda:

*“The person with HIV is assured that the responsibility to share is mine; the advantage of sharing is that there is another human being that accompanies me; and I decide what components I share with whom and when. In the process of encouraging disclosure, the health provider recognizes that the person with HIV retains his or her autonomy over decisions. But where there is fear of disclosure you try to change that by persuasion.”*²⁸

The aim of shared confidentiality is to promote better support, care and prevention for individuals, families and communities affected by HIV/AIDS. In communities where shared confidentiality has been a practice of community-based organizations, there has been an increase in community discussion of HIV/AIDS and

²⁸ Statement by Noreen Kaleeba, Founder TASO Uganda, presently UNAIDS Community Mobilisation Adviser, Geneva.

a decrease in the stigma and discrimination surrounding HIV/AIDS. It has therefore helped to open up the HIV/AIDS epidemic in positive and supportive ways.²⁹

Partner counselling by health care providers without consent

There will be some cases where an HIV-positive person (source client) does not wish to, and may refuse to, notify his/her partner(s) or allow them to be counselled by the health care provider. It is important to bear in mind that such refusal is most often due to a fear of rejection by partners and family, to fears of stigma and discrimination and/or to a fear of being blamed for the infection of others. It may also involve feelings of despair, remorse and guilt. Refusal to notify partners is *very seldom* due to a desire by the HIV-positive person to place another person deliberately at risk of HIV infection.

For some, the consequences of their HIV status becoming known by their partners are severe. This is particularly the case for women who live in societies where women suffer social, economic and legal disadvantages because they are women. In such places, a woman is often blamed for her own infection, as well as for the infection of her husband/partner, even though it is likely that she was infected by him. The reaction to disclosing her status may also include physical violence and abandonment, in which she (and her children) may be thrown out of the home and given no economic or social support. Thus, women may have very valid reasons for fearing to disclose their status to husbands/partners.³⁰

Given the possible serious consequences of counselling partners (discrimination, abandonment, violence) and of not counselling partners (transmission of HIV infection), counsellors and health care workers must be trained to handle the difficult ethical decisions to be made. In each case, all the potential harm and benefits of counselling or not counselling partners should be weighed. In most cases, with counselling and with a demonstration of support, the HIV-positive person will agree to notify partners. Initial support may take the form of notification in the presence of the counsellor and/or in the presence of another family member who will provide support, and protection if necessary. Furthermore, there should be follow-up and referral to other support services to ensure that the couple or family can cope with the HIV among them.

In cases where the source client refuses to notify, following repeated efforts to persuade him/her to do so, and where the failure to notify creates a danger to a partner whose identity is known to the counsellor (in legal language “an identifiable risk to an identifiable third party”), the counsellor should be authorized to counsel the partner(s)

²⁹ For further examples of community-based activities where the concept of shared confidentiality is exemplified, see *Comfort and Hope: Six Case Studies on Mobilizing Family and Community Care for and by People with HIV/AIDS*. UNAIDS, June 1999 (UNAIDS/99.10E); and Linkhoff P, Bukanga E, Syamalevwe B, Williams G. *Under the Mupundu Tree*. Actionaid Strategies for Hope (No.14), 1999.

³⁰ For more on these points, see Gielen AC, O’Campo P, et al. A women’s disclosure of HIV status: Experiences of mistreatment and violence in an urban setting. *Women’s Health*, 1997, 25(3):19-31; Van de Straten A, et al. Couple communication, sexual coercion and HIV risk reduction in Kigali, Rwanda. *AIDS*, 1995, 9:935-944; Temmerman M, Ndinya-Achola J, Ambani J, Piot P. The right not to know HIV-test results. *Lancet*, 1995, 345(8955): 969-970.

without the consent of the source client. In making this decision, the counsellor should ensure that the following factors are present.

- The HIV-positive person (source client) has been thoroughly counselled as to the need for partner notification/counselling.
- The counselling has failed to achieve the appropriate behavioural changes, including the practice of safe sex.
- The source client has refused to notify, or consent to the counselling, of his/her partner(s).
- A real risk of HIV transmission to the identifiable partner(s) exists.
- The source client is given reasonable advance notice of the intention to counsel by the health care worker.
- The identity of the source client is concealed from the partner(s) if this is possible in practice.
- Follow-up is provided to ensure support to those involved as necessary and to prevent violence, family disruption, etc.³¹

Recommendations for encouraging ethical partner counselling

Below are listed recommendations to create the enabling conditions to encourage the use of ethical partner counselling. Very important is the creation of a social and legal environment which promotes and protects the principles of non-discrimination, confidentiality, tolerance and compassion, as described in the previous section on beneficial disclosure. More specifically, to encourage ethical partner counselling, UNAIDS and WHO recommend the following:

- Develop national policies and public health legislation on partner counselling that protect the principles of confidentiality and informed consent, and provide for the limited and clearly defined circumstances under which partner counselling may take place without consent.
- Develop public health legislation that authorizes health care providers to decide, on the basis of each individual case and ethical considerations, whether to counsel partners without the consent of the source client, under certain circumstances.³²
- Hold consultations among health care providers, government and affected communities about how to encourage ethical partner counselling and protect people who disclose their status through such counselling.

³¹ Taken in large part from *HIV/AIDS and Human Rights, International Guidelines*, New York and Geneva, United Nations, 1998 (HR/PUB/98/1): 13, para. 28(g)

³² Ibid.

- Provide training and guidelines for health care providers and counsellors about how to protect confidentiality and informed consent in the context of partner counselling; how to encourage and assist voluntary partner counselling; how to make difficult ethical decisions in cases where there is refusal to counsel partners; and how to counsel partners in ways that harm is minimized and support is provided.
- Promote the establishment of professional ethical codes among health care and social service providers which require respect for confidentiality and informed consent in the context of partner counselling, and provide penalties for unethical conduct.
- Establish mechanisms for accountability and ways of making complaints in health care institutions and in communities when partners are counselled unethically by health care providers and other professionals.
- Support practical legal and social measures that address the vulnerability of people, particularly that of women, to stigma, physical violence and abandonment, including projects in the community which will assist in providing treatment, care, emotional support and protection from discrimination to those involved in partner counselling.
- Promote and support community projects about people's responsibility to protect themselves and others from HIV infection, particularly among men and boys.

5 Appropriate use of HIV case-reporting

Overview

Some countries have recently considered whether they should implement a policy of *named HIV case-reporting*. Under such a policy, health care providers would be required to report by name all HIV cases diagnosed by them to a health authority. (Other forms of case-reporting involve the use of a *code*, sometimes called a “unique identifier”, for each case; or provide information on cases *anonymously*.)³³ This has been promoted as a means to open up the HIV/AIDS epidemic; decrease denial; improve access to prevention and care services for those affected by HIV/AIDS; and obtain more accurate information on the prevalence and incidence of HIV and AIDS for surveillance purposes.

While *AIDS* case-reporting has been implemented in most countries, implementation of *HIV* case-reporting has been much more limited. Many countries started to collect information on HIV cases at the beginning of the epidemic but later dropped the practice when the infection became widespread. The reasons were the high cost and complexity of maintaining the system, the lack of effective treatment or preventive options once people were discovered to be HIV positive, and the small additional benefit for surveillance purposes.

However, there has been a recent trend in *high-income* countries to employ HIV, as well as AIDS, case-reporting. This trend is based on the fact that, where anti-retroviral therapies are available, the access to, and use of, these drugs has dramatically decreased the incidence of AIDS. As a result, AIDS cases are no longer an accurate base for calculating back to HIV incidence and prevalence. Furthermore, in these countries, case-reporting of HIV helps to monitor the access of those who are HIV positive to appropriate services and treatment, including the use of anti-retrovirals.

However, neither the reporting of HIV cases nor the reporting of AIDS cases, for the objectives listed above, has been useful in low-income countries. For surveillance purposes, data collected on the basis of case-reporting of HIV or AIDS have been problematic. In general, HIV/AIDS surveillance involves the routine collection, analysis and dissemination of accurate epidemiological information regarding the spread and distribution of HIV infection. Surveillance is an essential part of the response to the epidemic entailing a number of important objectives:

- to monitor trends in prevalence and incidence of HIV in populations;
- to assess disease burden in terms of morbidity and mortality due to HIV/AIDS;
- to be able to plan HIV prevention and care programmes directed at the particular epidemiological situation;
- to provide data for estimates and projections of the number of people with HIV/AIDS and AIDS-related mortality;

³³For more, see Annex 1, Definitions of important terms.

- to monitor the impact of the national response to the HIV/AIDS epidemic;
- to reinforce commitment to AIDS prevention and care through awareness of the numbers affected and their needs.

But the data obtained from HIV and AIDS case-reporting in many countries have not been useful for the stated objectives of surveillance largely for the following reasons.

- Less than 10% of HIV-positive people have been tested for HIV, so most are unaware of their status.
- Many people do not want to know their status, given the stigma and discrimination attached to a positive result and the fact that they will not have access to treatment or care.
- Among health care providers, there are problems with under-diagnosis and under-reporting of HIV and AIDS cases, including the fact that health care providers may be reluctant to report cases by name for reasons of confidentiality and privacy.
- In contrast, where the information is provided anonymously to avoid breaches in confidentiality, there is potential for multiple reporting of the same case.
- There is insufficient capacity and infrastructure to maintain confidentiality for either named or coded reporting, which further deters people presenting for tests.

These conditions make HIV case-reporting in resource-poor countries unreliable.

Advocates of HIV case-reporting point to potential benefits in terms of prevention and increased access to care. However, reporting HIV cases to health authorities does not necessarily lead to any additional benefit for either the client or the community, and may divert resources from more effective prevention and care strategies. Thus, where resources are limited, the appropriate balance must be found in the use of various prevention and care strategies that have different levels of costs and impact. Strategies such as public information campaigns, youth education and distribution of condoms are relatively cost-effective ways of reaching large numbers of people for prevention and care purposes. Case-reporting, however, is expensive, and does not increase access to prevention and care services in itself. To be effective in prevention and care terms, case-reporting must be meaningfully integrated into a host of HIV-related services, such as VCT, health and social support services for those HIV positive and/or presenting with AIDS-related illnesses, and greater access to HIV-related drugs and treatments. Resources should be put into developing these services before they are significantly diverted to case-reporting.

In light of these concerns, UNAIDS and WHO recommend HIV case-reporting only where certain conditions exist. These are:

- widespread access to, and use of, HIV testing;
- protection against breaches of confidentiality so as not to deter testing and reporting;
- access to effective care, including anti-retrovirals;

- capacity within the health system to collect accurate data, and to compile, analyse, and act upon them, including follow-up of cases.

However, even when these conditions do exist, HIV case-reporting needs to be associated with HIV prevalence studies in sentinel population groups and behavioural data to provide information of sufficient quality to monitor trends in the epidemic and the burden of disease.

In general, UNAIDS and WHO recommend that a country chooses appropriate HIV/AIDS surveillance in light of its needs and resources. This means surveillance that 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 results in regular and widespread dissemination of information on HIV/AIDS to the population in non-stigmatizing ways that help to open up the epidemic, decrease denial and discrimination, and increase commitment to prevention and care efforts. In resource-poor countries, depending on the state of the epidemic, this is likely to involve a form of sentinel surveillance (see description in Annex 1, Definitions of important terms). The WHO/UNAIDS *Guidelines for 2nd Generation HIV Surveillance* provide a comprehensive framework for consideration of surveillance options.³⁴

Recommendations for the appropriate use of HIV case-reporting

- In resource-poor countries where access to HIV testing and effective treatment is limited and where there is insufficient infrastructure to maintain confidentiality, avoid case-based reporting of HIV and employ sentinel surveillance within the framework of second-generation HIV surveillance.
- Where there is wide access to, and use of, HIV tests, established surveillance systems for communicable diseases, security and confidentiality of data, and access to anti-retroviral treatment, consider the use of HIV case-reporting to provide information to monitor HIV incidence and prevalence, and to increase access to treatment, patient compliance and long-term follow-up.
- Ensure that the surveillance methodology employed does not interfere with prevention or care activities, for example by allowing breaches of confidentiality that would make people afraid to take advantage of voluntary counselling and HIV-testing services.
- Ensure confidentiality and security of information through the development of policy, infrastructure (e.g. data storage and transmission systems that ensure the physical security of data and electronic security of computer files), increased capacity of health professionals to receive, report and use data, and legislation that protects against breaches of confidentiality.
- Increase public confidence in surveillance and protect the right to privacy through the enactment of regulations, policies and laws that preclude the non-public health use of data.

³⁴WHO/UNAIDS, 2000 (WHO/CDS/CSR/EDC/2000.5 and UNAIDS/00.03E/F/R).

- Where name-based or coded reporting is employed, assess periodically the extent to which incomplete reporting, incomplete diagnosis or duplication of cases is compromising the utility of the received data.
- In the use of sentinel surveillance that is unlinked, ensure that personal identifiers are removed from blood specimens in a way that does not permit relinkage.
- Strengthen the means and frequency by which the results of surveillance are disseminated in ways that open up the epidemic; reinforce prevention and care programmes; reduce fear, stigma and denial; and avoid the further stigmatization of certain groups of people, e.g. migrants, refugees, sex workers, men having sex with men.

6

Conclusion

People everywhere have great difficulty in openly facing issues involving sex, disease and death. In many countries, the stigma and discrimination surrounding HIV/AIDS adds to the fears that many people who are HIV positive or have AIDS feel about informing spouses, lovers, family, friends, colleagues – and even health care providers – about their HIV status. There is every incentive to keep HIV health status secret. In resource-poor countries, particularly, the fear of stigma, lack of treatment options, and the very limited access to voluntary counselling and HIV testing have led only a small number of people voluntarily to test for HIV and then disclose their HIV status for prevention of transmission or for care and support purposes. The fact that only a small number of people know they have HIV, and an even smaller number disclose that they are HIV positive, has added to the difficulty faced by governments and communities in creating greater awareness of the HIV/AIDS epidemic, encouraging people to come forward for testing, preventing further HIV infections and accurately monitoring HIV and AIDS on an ongoing basis.

It is clear that much more needs to be done to “open up” the epidemic so that conditions are created where HIV and AIDS become what they are – a viral infection and related illnesses that deserve, like any similar condition, a response involving compassion, support, respect and access to effective prevention, care and support options – for both the infected and the uninfected. This document has proposed some steps that can be taken to empower individuals and communities to engage in these activities – beneficial disclosure, ethical partner notification and the appropriate use of HIV case-reporting.

These steps adhere to the principles of confidentiality and informed consent, not only as valid ethical principles but also as pragmatic means by which to engage people in effective prevention and care efforts. Human rights and ethics have always been concerned with equity and with protecting both private and public interests. In the context of HIV/AIDS, human rights (right to privacy) and ethical principles (confidentiality and informed consent) are the basis to protect individuals and communities, first by creating an environment in which the greatest number of people will come forward for testing, counselling, prevention and care; and second by dealing in an ethical and effective manner with cases where people choose not to, or are unable to, inform partners about their infection. Mandatory measures are neither right, nor are they feasible or effective. They only serve to drive the epidemic further underground.

At this late, but crucial, stage of the epidemic, it becomes ever more important for communities, health authorities, governments and international agencies to work in partnership to encourage HIV testing and counselling, disclosure of status, notification of partners, and reporting on the epidemic in appropriate ways. This will involve a significant evaluation of the use of resources, and may involve reorientation from traditional HIV programmes. A serious shift must now be taken towards creating a social environment where people can feel confident and safe to test for HIV and inform others that they have HIV. This will mean different sorts of activities, such as public education campaigns on tolerance and non-discrimination, training of health care workers on ethics, implementation of more voluntary counselling and testing services, enactment of laws and policies protecting against discrimination, support for

community-based services that encourage VCT and follow-up support, and promotion of innovative concepts such as “shared confidentiality” and “positive living”. Many communities are already engaged in these activities and are showing a prevention and care success which involves the full community and allows the individuals in it to be able openly and positively to deal with HIV/AIDS. It is time now for countries and communities everywhere to move out from the darkness of secrecy into the light of effective individual and community action.

7

Annex 1 Definitions of important terms

Confidentiality

Confidentiality refers to the ethical and/or legal duty of the health care professional, and other professionals such as lawyers and social service providers, not to disclose to anyone else, without authorization, information that was given to, or obtained by, the professional in the context of his/her professional relationship with a client. It embraces intimate matters, which include sexual relationships, health status and illicit drug use. In the context of HIV/AIDS:

- Confidentiality applies to a person's HIV/AIDS status and requires that health authorities should seek the consent of the person infected for the disclosure of his/her HIV/AIDS status to others.
- Confidentiality also includes the expectation by a person with HIV/AIDS that his/her status will not be disclosed, without his/her consent, by other persons with whom that information may be shared.

The ethical duty of confidentiality is reinforced by the individual's right to privacy (see below).

Disclosure

In the context of HIV/AIDS, disclosure refers to the act of informing any individual or organization (such as a health authority, an employer or a school), of the serostatus of an infected person, or it refers to the fact that such information has been transmitted, by any means, by the person him or herself, or by a third party, with or without consent.³⁵ Except in exceptional circumstances, when disclosure to another person is required by law or ethical considerations, the person with HIV has the right to privacy and to exercise informed consent in all decisions about disclosure of his/her status.³⁶

³⁵ From *Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS, Public Health and Human Rights Implications*. Geneva, WHO/UNAIDS, June 1999 (UNAIDS/00.26E).

³⁶ An example of disclosure that might be permitted or required by law is disclosure where people accused and/or found guilty of sexual offences are required to disclose their HIV status to victims of their (presumed) offences.

HIV/AIDS counselling

HIV/AIDS counselling is a confidential dialogue between a client and a care provider which is aimed at enabling the client to cope with stress and take personal decisions, including those regarding prevention and care, related to HIV/AIDS. The counselling process involves an evaluation of personal risk of HIV transmission and facilitates preventative behaviour.

Pre-test HIV/AIDS counselling is a dialogue between a client and a health care provider aimed at discussing the HIV test and the possible implications for the client of knowing his/her HIV status, which leads to an informed decision to take, or not to take, the test.

Post-test HIV/AIDS counselling is a dialogue between a client and a health care provider aimed at discussing the HIV test result and providing appropriate information, support and referral, and at encouraging behaviour that reduces the risk of becoming infected, if the test is negative, or reduces the risk of transmitting HIV to others, if the test is positive.³⁷

Incidence

The number of new cases arising in a given period in a specified population.

Informed consent

Informed consent is based on the principle that competent individuals are entitled to make informed decisions regarding their participation in, or acquiescence to, certain events in the context of a professional relationship between health care provider and patient/client. Informed consent protects the person's freedom of choice and respects his/her autonomy, particularly with respect to decisions affecting his or her body and health. In the HIV/AIDS field, health care professionals have an ethical duty to obtain informed consent in order to administer HIV tests and other HIV/AIDS-related health care interventions, and before disclosing to others any HIV-related information concerning a patient/client, including HIV status.

Notifiable disease

A disease that by law must be reported to the public health authority, or other designated authority in the pertinent jurisdiction, when a diagnosis is made.

³⁷See *Voluntary Counselling and Testing Technical Update*. Geneva, UNAIDS, May 2000, (WC 503.6).

Partner counselling (partner notification, partner management, contact tracing)

Partner counselling or notification is the process of contacting the sexual partners (or drug-injecting partners) of an individual (source or index client or patient) who has a sexually transmitted infection (STI) including HIV, and advising the partners that they have been exposed to infection. By this means, people who are at high risk of STI/HIV, many of whom are unaware that they have been exposed, are contacted and encouraged to attend counselling, testing and other prevention and treatment services. Where possible, confidentiality is maintained by not providing the name of the source client to partners.

In most cases, partner counselling is carried out with the informed consent of the source client or provider. A situation where partner counselling might be permitted without consent arises when a health care provider is aware that a person with HIV is behaving in a manner that is placing another person at direct risk and refuses, after extensive counselling, to permit partners to be contacted. It then becomes an ethical duty of the health care provider to decide how to prevent the greatest amount of possible harm to the parties involved, given the individual circumstances of the case. For further discussion, see text at pages 21-23.

Partner counselling can be undertaken by the source client partner him or herself, by the health care provider, or through the combined efforts of both.

Source referral: the source client or patient is encouraged to contact his or her sexual (or drug-injecting) partners and advise them to seek appropriate medical care. This process can be assisted by health care workers who spend time educating the source client or patient about the importance of contact tracing, give out contact cards, or by using telephone or mail reminders.

Provider referral: the health care provider involved in the source client's or patient's care can counsel the sexual partners without naming the source concerned.

Conditional referral: the health care provider of the source client or patient obtains names of sexual partners but allows the client a period of time to counsel partners him/herself. If the partners are not counselled within this time period, the health care provider counsels the partners without naming the source patient or client concerned.³⁸

³⁸ Largely taken from *Questions and Answers on Reporting, Partner Notification and Disclosure of HIV Serostatus and/or AIDS, Public Health and Human Rights Implications*. Geneva, WHO/UNAIDS, June 1999 (UNAIDS/00.26E). See also *Report of the Consultation on Partner Notification for Preventing HIV Infection*. WHO, 1989 (WHO/GPA/ESR/89.2).

People living with HIV/AIDS (PWHA)

Often this term has been used to refer to people actually infected with HIV and/or experiencing AIDS-related illnesses or infections. More recently there has been a move to broaden this term to include those also *affected* by HIV/AIDS, but not necessarily infected. Thus, the term would include infected people, people with the symptoms of AIDS and also HIV-negative partners, family members and close friends.³⁹ In this document, when there has been a need to refer only to those who are infected with HIV, the term “HIV positive” has been used.

Prevalence

The number of cases in a given population at a specified point in time.

Public health surveillance

Public health surveillance is the collection of information on the distribution and spread of infection of sufficient accuracy and completeness to be pertinent to the design, implementation and/or monitoring of prevention and control programmes and activities. There are several methods of surveillance of HIV.⁴⁰ These include:

- **Population-based surveillance.** This form of surveillance involves the collection and testing for HIV of blood specimens from a random sample of the population being studied. It also permits the collection of more detailed information, particularly on risk behaviours. Unlike sentinel surveillance studies, described below, population-based studies normally require that health authorities obtain the informed consent of all the people whose blood is used. This increases the cost of this form of surveillance and creates a potential for participation bias. Though population-based surveillance may be the best way to assess HIV prevalence, this form of surveillance is expensive and complex and has so far been implemented in few countries.
- **Sentinel surveillance.** Sentinel surveillance is the systematic collection of data on incidence or prevalence of HIV infection in selected populations. It may involve the use of the blood of people in a particular hospital, geographic area or population group (e.g. sex workers or migrant workers). Some sentinel groups (e.g. pregnant women, military recruits) may be used as proxies for the general population. The data that are collected may be either linked (traceable by a code to an individual) or unlinked (untraceable and anonymous). If data are linked, then informed consent is required. Unlinked anonymous testing involves the testing for HIV of blood collected routinely for other purposes (e.g. blood donation, antenatal attendance) on a regular basis. In this case, there is no need for individual informed consent, and participation bias is minimized. This is the most commonly used form of HIV surveillance.

³⁹For more on this, see *Greater Involvement of People Living with or Affected by HIV/AIDS* (GIPA). September 1999, (UNAIDS/99.43E).

⁴⁰For full description of HIV surveillance, see *Guidelines for 2nd Generation HIV Surveillance*. Geneva, WHO/AIDS, 2000 (WHO/CDS/CSR/EDC/2000.5 and UNAIDS/00.03E/F/R).

- **Case-based surveillance.** This form of surveillance is based on an often legal requirement that health care providers report to health authorities every case of HIV and/or AIDS that they have diagnosed. Information is provided using a standard reporting form. The report may contain the *name* of the case (named reporting); or may use a *code* (sometimes called a “unique identifier”) for each case; or may provide information on cases anonymously. Health care providers may sometimes be reluctant to report cases identified by name for reasons of confidentiality and to protect patient privacy. On the other hand, where the information is provided anonymously, there is potential for multiple reporting of the same case.

Reporting

Refers to the procedure through which health providers systematically inform health authorities of each individual case of HIV infection and AIDS presenting in consultation, or otherwise known to them. Where HIV and AIDS are notifiable diseases, this is required by law.

- **Named case-reporting.** The names of individuals with HIV infection and/or AIDS are provided. The information is confidential and is intended only for the health system to ensure that appropriate action is taken.
- **Unnamed case-reporting.** Names of individuals with HIV infection and/or AIDS are removed, and health authorities are provided only with information that is useful for disease surveillance and analysis (for example, age, gender, risk factors, occupation). When possible, an identifying code is used in order to avoid duplicate reports (reporting as separate cases of HIV infection and/or AIDS each time the same individual presents for care).⁴¹

Right to privacy

The right to privacy is reflected in several international human rights instruments, as well as in some national bills of rights. For example, Article 17 of the International Covenant on Civil and Political Rights provides: “No one shall be subjected to arbitrary and unlawful interference with his privacy, home or correspondence, nor to unlawful attack on his honour and reputation. Everyone has the right to protection of the law against such interference or attacks.”⁴² This right creates an obligation on States to promote, protect and fulfil it by ensuring that the State does not arbitrarily interfere with private matters; that others do not infringe this right; and that the State takes necessary legal or other measures to protect people’s right to privacy.

⁴¹ Ibid. See footnote 5.

⁴² Adopted by the General Assembly under GA resolution 2200 (XXI), UN GAOR, 21st session, Supplement No. 16, UN Doc. A/6316 (1966). Entered into force 23 March, 1976.

8

Annex 2

General guiding principles

UNAIDS and WHO are UN-system agencies dedicated to the promotion of health, human rights and ethical principles. As such, they work with and call upon governments to promote, protect and implement the international human rights obligations found in international human rights instruments,⁴³ and the ethical principles found in various texts on ethical principles.⁴⁴ In the context of the subjects of this paper – disclosure, partner counselling, and HIV case-reporting – UNAIDS and WHO promote the following general principles when governments and policy-makers plan appropriate national strategies.

- People living with HIV/AIDS and affected communities should be consulted and involved in decision-making, policy formulation, programme planning, implementation and evaluation.
- Respect and protection of human rights and ethical principles (e.g. the right to privacy, confidentiality, informed consent, the duty to do no harm) will directly facilitate the acceptance, implementation and success of HIV prevention and care measures – particularly if they require the active participation of the community. On the other hand, measures that erode human rights and ethics and create an environment of fear, intolerance and coercion will undermine public health interventions that aim to encourage disclosure, partner counselling and appropriate use of HIV case surveillance.
- Human rights and ethical principles should be upheld in every policy. If limitations of human rights are to be justifiable, these limitations should be prescribed by law and not be arbitrary. They should be strictly necessary for the attainment of a legitimate goal, and be the least restrictive measure to achieve this purpose.
- Policies and programmes should be assessed on the basis of the following parameters:
 - whether the proposed policy or programme can be effectively implemented;
 - whether it is a rational allocation of resources in light of other competing needs;
 - the benefits and possible adverse consequences of a policy both for individuals and for broader public health and social goals;
 - whether the benefits outweigh the harm;
 - whether the longer-term consequences of policy decisions are beneficial.

⁴³ For a full explanation of relevant human rights in the context of HIV/AIDS, see United Nations, *HIV/AIDS and Human Rights, International Guidelines*. New York and Geneva, 1998 (HR/PUB/98/1).

⁴⁴ There are many relevant ethical codes. For example, see International Code of Medical Ethics, World Medical Association, 1949, 1963, 1983; The Hippocratic Oath; The World Medical Association Declaration of Helsinki, adopted in 1964 and most recently amended in 1989; the International Ethical Guidelines for Biomedical Research Involving Human Subjects, CIOMS, Geneva, 1993; Ethical Considerations in HIV Preventive Vaccine Research UNAIDS, 2000 (UNAIDS/00.07E).

- Data collection, collation, analysis and dissemination should be undertaken for a specific and valid purpose, namely to enable appropriate and constructive action for the prevention and control of the epidemic and provision of care for and support of people infected, affected and vulnerable to HIV/AIDS.

9

Annex 3

List of recommendations

To encourage beneficial disclosure

- Conduct public information campaigns and community forums aimed at promoting tolerance, compassion and understanding, and reducing fear, stigma and discrimination.
- Encourage participation of people living with HIV/AIDS in public information campaigns and in HIV programmes and policy formulation.
- Establish more voluntary counselling and testing (VCT) services, including services in rural areas and for marginalized groups.
- Support governmental agencies, non-governmental organizations and community-based organizations to make community-based services, including VCT, family outreach, community support, positive living, support groups and care options more widely available.
- Encourage the media to report on HIV/AIDS in a responsible, non-discriminatory and non-sensational manner.
- Train health care workers in the management of HIV and universal precautions, in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train other professionals (social workers, police, lawyers, judges) in attitudes of non-discrimination, acceptance and compassion, and in the principles of confidentiality and informed consent.
- Train key personnel in non-health employment settings, including human resource management in industry, in promoting non-discriminatory practices in the workplace.
- Enact or reform laws, administrative guidelines and professional codes of conduct to prohibit discrimination and breaches of confidentiality related to HIV status.
- Create legal support services for those who have suffered discrimination based on HIV status.

To encourage ethical partner counselling

- Develop national policies and public health legislation on partner counselling that protect the principles of confidentiality and informed consent, and provide for the limited and clearly defined circumstances under which partner counselling may take place without consent.
- Develop public health legislation that authorizes health care providers to decide, on the basis of each individual case and ethical considerations, whether to counsel partners without the consent of the source client, under certain circumstances.
- Hold consultations among health care providers, government and affected communities about how to encourage ethical partner counselling and protect people who disclose their status through such counselling.
- Provide training and guidelines for health care providers and counsellors about how to protect confidentiality and informed consent in the context of partner counselling; how to encourage and assist voluntary partner counselling; how to make difficult ethical decisions in cases where there is refusal to counsel partners; and how to counsel partners in ways that harm is minimized and support is provided.
- Promote the establishment of professional ethical codes among health care and social service providers which require respect for confidentiality and informed consent in the context of partner counselling, and provide penalties for unethical conduct.
- Establish mechanisms for accountability and ways of making complaints in health care institutions and in communities when partners are counselled unethically by health care providers and other professionals.
- Support practical legal and social measures that address the vulnerability of people, particularly that of women, to stigma, physical violence and abandonment, including projects in the community which will assist in providing treatment, care, emotional support and protection from discrimination to those involved in partner counselling.
- Promote and support community projects about people's responsibility to protect themselves and others from HIV infection, particularly among men and boys.

To encourage the appropriate use of HIV case-reporting

- In resource-poor countries where access to HIV testing and effective treatment is limited and where there is insufficient infrastructure to maintain confidentiality, avoid case-based reporting of HIV and employ sentinel surveillance within the framework of second-generation HIV surveillance.
- Where there is wide access to, and use of, HIV tests, established surveillance systems for communicable diseases, security and confidentiality of data, and access to anti-retroviral treatment, consider the use of HIV case-reporting to

provide information to monitor HIV incidence and prevalence, and to increase access to treatment, patient compliance and long-term follow-up.

- Ensure that the surveillance methodology employed does not interfere with prevention or care activities, for example by allowing breaches of confidentiality that would make people afraid to take advantage of voluntary counselling and HIV testing services.
- Ensure confidentiality and security of information through the development of policy, infrastructure (e.g. data storage and transmission systems that ensure the physical security of data, and electronic security of computer files), increased capacity of health professionals to receive, report and use data, and legislation that protects against breaches of confidentiality.
- Increase public confidence in surveillance and protect the right to privacy through the enactment of regulations, policies and laws that preclude the non-public health use of data.
- Where name-based or coded reporting is employed, assess periodically the extent to which incomplete reporting, incomplete diagnosis or duplication of cases is compromising the utility of the received data.
- In the use of sentinel surveillance that is unlinked, ensure that personal identifiers are removed from blood specimens in a way that does not permit relinkage.
- Strengthen the means and frequency by which the results of surveillance are disseminated in ways that open up the epidemic; reinforce prevention and care programmes; reduce fear, stigma and denial; and avoid the further stigmatization of certain groups of people, e.g. migrants, refugees, sex workers, men having sex with men.

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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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