

Questions and answers on reporting, partner notification and disclosure of HIV serostatus and/or AIDS

Public health and human rights implications

World Health Organization

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Four points on the position of WHO and UNAIDS

- Reporting, partner notification and disclosure of HIV/AIDS are procedures which are undertaken for a variety of purposes. They are procedures which are not always clearly defined and they take many different forms. The ways in which they are carried out depend on intended purpose, social context, characteristics of the individual or population group concerned, regulations in place, including those for the protection of human rights, organization of health services, resources available, and prevalence of HIV. Recommendations on policy will be based on careful analysis of all these factors.
- As UN bodies, the role of WHO and UNAIDS is to advise States on public health policies that ensure respect for human rights. The AIDS epidemic has demonstrated that public health interest and respect for dignity and human rights are linked concerns. There is no antagonism between the two; sound policies and effective strategies must address them in synergy.
- WHO and UNAIDS recognise the importance of reporting and partner notification issues in relation to HIV/AIDS and understand the concerns of governments on this matter. We are gathering evidence on laws and policies and their impact from all parts of the world in order to provide a solid foundation for the formulation by governments of reporting and partner notification policies that fulfil their stated purpose, can be implemented safely and effectively and are in accordance with human rights standards.
- Governments need first and foremost to consider the intended purpose of proposed laws and policies. They must then examine the evidence that the intended purpose is, in fact, served by the proposed laws and policies; and assess the feasibility of their implementation and their likely positive and negative impact on individuals and societies.

** The term HIV/AIDS is used in this document to refer to HIV and/or AIDS*

Note to the reader

Reporting, partner notification and disclosure are distinct procedures or actions (see the definition of terms at the end of this document), with rather different implications for human rights and public health. There is much overlap between them in terms of their implications but for the sake of clarity and convenience, they are dealt with in two sections in this document:

- **Reporting of HIV infection and/or of AIDS cases to health authorities**
- **Notification of HIV and/or AIDS status mainly to partners but also to family, friends or care providers.**

Disclosure is a general term referring to the act of informing persons or authorities of an individual's serostatus or to the fact that such information has been transmitted to a third party, with or without the individual's consent. The term disclosure may be used in the context of both reporting and partner notification. Disclosure outside the health system should not but does occur through reporting of cases of HIV infection and/or of AIDS,

informally, either intentionally or unintentionally. Disclosure to selected individuals, is of course an explicit and integral part of partner notification.

There is some confusion between partner notification and notification of disease to health authorities. In this document, the term notification is used to refer to notification to partners and sometimes to family, friends or care provider. The term reporting is used to refer to notification to health authorities.

Section I: Reporting of HIV infection and/or of AIDS cases

Isn't case reporting of HIV and/or AIDS the best way of obtaining accurate and complete epidemiological information for policy and planning?

Reporting of HIV and reporting of AIDS are very different. Asymptomatic HIV infected people can only be diagnosed and reported if they have been tested for antibodies. People with AIDS have usually presented at a health facility with clinical symptoms. Until recently, case reporting of AIDS has been used for back-calculation of HIV prevalence. Since antiretroviral (ARV) treatments became the standard of care in developed countries, AIDS case reporting has become less useful in those countries (see below) and HIV reporting is being introduced.

For a variety of reasons, *AIDS case reporting* by health providers to health authorities has not proven to be very useful for obtaining epidemiological information. The long, symptom-free incubation period means that most HIV-positive people are unaware of their infection and do not present for testing – when such facilities are available. Amongst those who suspect they might be infected, many may not wish to know their serostatus, particularly in situations where no care or support is available. It is estimated that only 5% of HIV positive people worldwide are aware of their infection. This is what is meant by the "tip of the iceberg" in relation to reported and actual numbers of HIV infections and/or AIDS cases.

A drawback with *HIV case reporting* for surveillance purposes is that the number of cases reported depends on levels and targeting of HIV testing in the country or area. Testing is often restricted to certain groups such as military recruits, sex workers or STD clinic attenders, providing little or uneven information about levels of infection in the general population. In developed countries where 75-80% of HIV infected individuals have been tested, reporting can provide accurate information. In most developing countries where less than 10% of infected individuals are tested, the information is inaccurate and greatly biased towards groups regularly screened or at higher risk.

How can information for public health surveillance purposes be obtained if not through case reporting?

There are better and cheaper ways of obtaining epidemiological information than through case reporting. One of these is sentinel serosurveillance which is a simplified scheme designed to describe the current HIV situation in a country or region and to monitor future trends. It involves repeated sampling at designated sites for selected groups and allows detection of changes in the incidence, spread and distribution of disease which is the primary objective of public health surveillance. To avoid participation biases, HIV sentinel surveillance uses unlinked anonymous screening, in which blood collected for other purposes is tested for HIV.

There is no need for informed consent and counselling as there is no way to link the test result with the individual tested. The method poses certain ethical problems in that individuals cannot be informed of their serostatus. It is therefore essential to provide access to voluntary and confidential testing. Unlinked anonymous screening is an accurate and effective method for public health surveillance which does not endanger or compromise the broad principles of public health and human rights.

Shouldn't all cases of HIV/AIDS be reported to health authorities in the public health interest – to prevent further spread of infection or to encourage people to seek care?

Where most or all cases of HIV could be reported at a reasonable cost and without any adverse consequences for individuals and communities including the violation of human rights, (discussed below) the answer might be yes. But we would still need to know that case reporting actually prevents further spread of infection and/or facilitates entry into care. No evidence is currently available to show this. If only a small number of HIV infected people are tested, reporting is in any case unlikely to have an impact on prevention and care.

It is important for governments to keep in mind that a major objective in their response to HIV/AIDS is to encourage people to come forward for testing. As discussed above, the best way to do this is through voluntary and confidential counselling and testing.

What does case reporting involve and how much would it cost?

The quality and quantity of HIV case reporting data are directly dependent on HIV testing policies and practices in place. In the interests of public health and respect for human rights, there is wide agreement now that testing should only be offered and undertaken if it is accompanied by supportive and follow up services – counselling, clinical and psychosocial care, education for prevention etc. In a number of countries it is a requirement to offer anonymous testing facilities everywhere irrespective of any other activities undertaken to obtain data for surveillance or other purposes.

Case reporting then, undertaken in accordance with public health and human rights principles, implies a set of services including of course voluntary counselling and testing, and all related health and social services required to provide care for HIV infected people at all stages of illness. The real costs involved therefore are not limited to the procedures, clerical staff, equipment and facilities required to report cases to health authorities.

Extending HIV testing and counselling centres and screening programmes in developing countries to ensure that the majority of HIV infected have access to these services requires a substantial investment in staff, equipment, facilities and training. The benefit of this investment in terms of HIV prevention should be weighed against the potential benefit of investing the same resources in other preventive activities of proven efficacy, such as school AIDS education, condom promotion and social marketing, and diagnosis and treatment of other sexually transmitted infections (STIs).

Isn't accurate epidemiological information the cornerstone of an effective response and the first step in slowing the spread of the epidemic?

As in all areas of health, it is important to have accurate information on the extent and distribution of disease in order to formulate appropriate and effective policies and strategies for the provision of care and support and prevention of further spread. Policy makers and health planners need an assessment of the nature and extent of the problem of sufficient accuracy and completeness to allow them to take effective action. But it is neither necessary nor possible to obtain perfectly accurate and complete information. It is also very costly and would divert scarce resources from selected proven interventions known to have an impact on transmission of infection.

Confidentiality can be respected in case reporting to health authorities, whether named or unnamed. Why is there such concern about human rights violations in relation to reporting?

In practice, it is extremely difficult to protect confidentiality when cases are reported by health providers to health authorities, whether the reporting is named or unnamed. Coding is normally required to avoid duplicate reporting, particularly with HIV. For surveillance purposes, there is no need for named reporting as long as unique identifiers are used.

Concern about unauthorized disclosure ("leaking") of information has led to the development of systems to unlink/remove names from records, usually through the use of identifying codes and sometimes through anonymous reporting.

The main advantage of unnamed reporting is that it may offer some protection of confidentiality. The main disadvantage is that it increases errors of duplication because of reporting from different health and social services. Ensuring on the one hand, accuracy and completeness of data and on the other hand, the security and confidentiality of HIV and AIDS data requires sophisticated information technology including data protection systems, and enforceable confidentiality regulations and laws at local and national level. Such systems are in place only in countries with very well developed and well resourced health and legal systems.

Named reporting allows for better coordination between services and, to the extent that the information remains within health and related services, the advantage in terms of well organized care and support may be considerable. But experience has shown that risks of unauthorized disclosure to individuals or organizations outside health and social services are high - even with unnamed reporting. The consequences of such disclosure

can be very serious, as described above, and in many countries, fear, stigma and discrimination are still major problems. Countries must carefully assess the evidence that case reporting contributes to any of the three intended purposes namely, surveillance, prevention or care, and weigh this against the negative effects on public confidence of risks of information "leakages".

Many industrialized countries are introducing reporting of HIV infection as well as of AIDS cases. Why should developing countries not do the same?

In industrialized countries where this is the case, advances in treatment, notably the introduction of antiretroviral treatments for HIV infection, have slowed the progression of HIV disease and contributed to a decline in AIDS incidence. This has meant that AIDS surveillance data can no longer be used to back calculate HIV incidence nor do they provide a useful indication of the impact of HIV/AIDS on the health care system. In addition, funding for HIV/AIDS programmes is often linked to the reported number of either HIV or AIDS cases. The extension of national surveillance to include both HIV infection and AIDS is the result of these recent developments.

These developments are extremely unlikely to occur in the near future in countries which are hardest hit by HIV/AIDS as only a small percentage of cases are reported and ARV drugs are not available to the vast majority of HIV infected people. The benefit of HIV reporting in these circumstances would be very limited for surveillance, prevention or care purposes. Increasing access to all treatments for HIV/AIDS including drugs for common HIV-related illnesses is an area requiring urgent attention.

Couldn't case reporting be a useful and cost saving linkage between surveillance systems and prevention and care services?

It appears to make good sense to share and use information between services *whatever its source*. But this may not be the case. Partner notification and referral services are the most obvious linkage activities which might be considered. As discussed above, these are activities which must be undertaken voluntarily and confidentially, through counselling which can be intensive, time consuming, and involve the exchange of very personal, sensitive information. It is all the more important that information relating to this kind of individual care not be linked to data bases other than those strictly concerned with the person's physical and emotional wellbeing.

Decisions about such linkages need to be carefully considered taking into account the degree of protection that can be assured, the need to coordinate with other services, and the usefulness either for care and prevention programmes or for surveillance purposes. The guiding principle must be that linkages between surveillance systems on the one hand and prevention and care services on the other, should not interfere with or undermine their respective primary functions. The quality, confidentiality and voluntary nature of prevention services and the quality and security of the surveillance system must not be compromised.

What about patient records? Isn't this an essential component of health care and patient management?

The importance of complete and up-to-date patient medical records is not in question in this debate. This is a health service issue, with no necessary implications for surveillance. The normal procedures for respecting patient privacy need to be strictly followed allowing for the possibility of transmitting information between different services, in the interests of individual patient management, for example for treatment of dual infection with tuberculosis or for blood transfusion safety. Patient records are extremely valuable in terms of the qualitative information they contain for the design, implementation and evaluation of prevention and care interventions.

Section II: Partner notification and notification to family, friends or care providers

Isn't partner notification one of the most effective ways of breaking the chain of transmission of sexually transmitted infections? In what way is HIV different?

Applied on a voluntary basis (i.e., when the infected patient has given explicit consent to notification of partners either by her/himself or by the health provider; see also *Definition of Terms*), partner notification is an important way of protecting the uninfected partner, providing the information necessary to take protective action and an

opportunity for education for prevention. It is also an important way of helping the already infected partner in terms of access to early treatment and care. Voluntary and confidential partner notification should be part of the standard of HIV/AIDS care, accompanied by psychosocial and medical care and support, including counselling, in a supportive environment which provides legal, material and social protection from negative consequences of disclosure.

Public health experience in control of sexually transmitted infections shows that partner notification carried out mandatorily is a relatively ineffective means of "breaking the

chain of transmission" when there is considerable delay before contacts can be traced, when sex with partners other than the regular partner is common, and when health services are inaccessible or unacceptable to clients. These are lessons which can be applied to HIV infection which has a very long incubation period and is often associated with sex outside primary relationships.

However, there are important distinctions between HIV infection and other STIs which have implications for public health policy. Unlike syphilis and gonorrhoea for example, HIV infection is not curable, and in many parts of the world, treatment and care are unavailable to the majority of those infected. It is ultimately fatal. Furthermore, there is tremendous fear and stigma in relation to HIV/AIDS which works against effectiveness of partner notification policies.

Is there strong evidence that partner notification is more effective when implemented voluntarily than mandatorily?

The evidence that partner notification approaches are more effective when carried out on a voluntary rather than mandatory basis stems from combined experience in the history of sexually transmitted diseases and, more recently, HIV. More evidence must be drawn from past experiences, and WHO and UNAIDS are currently trying to collect relevant data. There is no strong evidence that mandatory approaches to notification are more effective than voluntary approaches.

The issue of voluntary versus mandatory must be examined from a combined health and human rights perspective. Governments are responsible for the protection and promotion of public health, as well as for the protection and promotion of human rights. Thus, they have the obligation to devise public health strategies and policies that are respectful of human rights. There are situations, however, where certain rights can be restricted for the sake of public health. This must be done carefully and in accordance with defined criteria (see below). The mandatory treatment of tuberculosis in practice in some countries illustrates this point.

The burden of proof that the restriction of certain human rights in order to protect public health is necessary, rests with the government, and this evidence must be produced before, not after, the enactment of policy which restricts rights.

Does partner notification lead to behaviour change and risk reduction? Does it reduce incidence or prevalence of HIV/AIDS?

There are no published studies on the effectiveness of partner notification in helping partners adopt safer sexual behaviour. But it has been shown that partner notification has little effect on high risk behaviour unless it is accompanied by preventive services and intensive counselling. One multi-site study has shown that people will reduce their risks and change their behaviours following voluntary counselling and testing, and to a lesser extent following provision of health information.

The effectiveness of partner notification in terms of actual reduction in incidence and prevalence of either STIs or HIV has yet to be measured.

Is forcing people to notify their partners effective in bringing more people forward for testing and treatment?

Public health experience shows that when people know that they will be asked to notify their partner(s), they are less willing to come for testing, treatment or counselling themselves. The net result then is that fewer people present at health centres, those that are infected continue to spread the infection to their partners, and care is not available to them or their partners.

In fact, when there is any element of coercion, the trust and cooperation that are essential to effective implementation of public health policy tend to be undermined, the problem goes underground and this makes prevention and care efforts almost impossible.

It has been shown on the other hand, that most people who accept to come for testing and counselling by themselves are willing to identify or inform at least some of their partners voluntarily.

It seems likely that the deterrent effect of forced notification on testing and treatment may result in greater spread of infection than that which would result from the absence of such a policy.

Should legislation be enacted to force HIV-positive people to name their partner(s) about their infection?

No, such legislation should not be enacted. WHO and UNAIDS strongly advocate, rather, for counselling of HIV-positive people on the importance of informing their partners and on their responsibility for the protection of their partner(s) health and their own.

It is ***impossible in practice*** (irrespective of whether it is right or wrong) to force people to notify or even name their partner(s). People cannot always identify all the partners they have had over a long period; and in some cases they may not know their names. If they do not wish to name certain or all of their partners, the health provider has no means of obtaining this information. Even when health providers have names and addresses of partners, they are usually able to trace and warn only a very small proportion of these.

Isn't partner notification by the infected person the best way to protect uninfected partners?

On a voluntary basis, it is a very important way. It should be part of the standard of HIV/AIDS care. However, it is not a public health measure that can be applied in isolation. Any sort of partner notification must be accompanied by psychosocial and medical support and it must take place in a supportive environment which provides legal and material protection from the negative consequences of disclosure, including advocacy within the community for social support.

It must be remembered that in many instances, particularly for women, the partner is already infected and indeed may be the source of infection in the index patient. The majority of HIV positive women in Africa have been infected by their only partner/husband.

Finally, there are other ways of protecting uninfected partners. These include the promotion of safer sex, including the use of condoms, reducing the number of partners and abstinence. Many of these prevention interventions are tried and proven, are more cost effective than partner notification, and need to be widely implemented as key control strategies.

What about the right to know of spouses/partners? Isn't it the duty of health authorities to inform and "protect" them?

The first duty of health authorities is to promote and protect public health, to implement laws and policies which are based on strategies that have been shown to protect and/or improve the health of the general population, and which meet human rights standards.

At the level of health authorities, the protection of individual health has to be considered within the larger context of the health of the general public. Situations will arise when the immediate interest of an individual appears to be neglected in favour of public health principles. Individual rights for example, may sometimes be restricted in the interests of controlling infectious disease.

In contrast, health professionals' first duty is towards their patients, ie the protection of individual health. Health professionals provide health services within a public health framework that has been designed to protect the general good. Within that framework, health professionals have various duties relating to the protection of the health and wellbeing of individuals, including both the duty to respect confidentiality and the duty to warn of a risk of infection.

Situations arise in which these duties appear to be in conflict, for example, when health professionals cannot obtain explicit consent from a source patient to notify the spouse or partner about risk of infection, but

recognises the ethical obligation to do so. Guidelines (see below) have been developed to assist health professionals in making these difficult decisions, so that the "right to know" can be respected and spouses and partners can be protected.

Why is confidentiality so important?

Assurance of confidentiality is a precondition for most people to come forward for testing and treatment for HIV/AIDS. Experience has shown that people must know and have complete confidence that their privacy will be respected because the possible negative consequences of disclosure may outweigh any advantage to them of being tested – even if they are positive.

Confidentiality can be understood to be protected under the human right to privacy. The United Nations Commission on Human Rights has recently reinforced the importance of this aspect of human rights in relation to HIV/AIDS in a resolution adopted by more than 50 countries on 21 April 1999 which *invites States to strengthen national mechanisms for protecting HIV/AIDS related human rights and to take all necessary measures to eliminate stigmatization of and discrimination* against those infected and affected, especially women, children and vulnerable groups so that infected persons who reveal their HIV status, those presumed to be infected, and other affected persons are protected from violence, stigmatization and other negative consequences. (UN Economic and Social Council: E/CN.4/1999/L.72)

Any violation of the right to privacy threatens to destroy the trust and cooperation that are essential for effective implementation of public health policy. Privacy is a right which can be restricted but only under certain conditions. In the absence of a treatment which makes a person uninfected, a successful public health response to the epidemic is unavoidably dependent on the willingness of those at risk to voluntarily comply with public health messages.

Are protection of confidentiality and the promotion of open, accepting attitudes about HIV/AIDS incompatible?

They are not incompatible. There has been some confusion over the need to combat denial and silence – to "normalise" HIV/AIDS - and the need to guarantee confidentiality. These are very different issues which do not run counter to each other.

It is very important to distinguish between the promotion of open discussion about HIV/AIDS and non discrimination at community and society level, and the need for confidentiality, both of which contribute to the public health interest in providing care and support and in decreasing transmission.

Secrecy, as a societal reaction to a stigmatized disease, needs to be combated, for example through public information, advocacy and education through people living with HIV/AIDS, and more accurate reporting of cases, including citing HIV/AIDS as the primary or secondary cause of death on death certificates.

Respect for confidentiality does not reinforce secrecy. On the contrary, any abandonment of the principle of strict confidentiality is likely to drive the problem underground and make it more "secret" and less amenable to control.

What are the potential negative consequences of disclosure of HIV status to others?

Disclosure, particularly for women, may result in violence and/or abandonment by partner, family or community. Both men and women have suffered discrimination when their HIV status became known, including loss of job and income, of housing rights and of other entitlements, and social stigmatization which all add to the suffering related to the illness itself.

These negative consequences may well outweigh the advantages of informing a partner. In situations where treatment and care are unavailable and where it is extremely likely that the partner is also infected (may already have symptoms and signs of HIV-related illness), partner notification and/or disclosure may bring little benefit.

Are the consequences of disclosure different for women and men? Should there be different recommendations for women and men?

There is evidence that disclosure of positive HIV serostatus is connected with violence against women. The risk of physical or other harm to an HIV-positive woman from her partner may be greater than the potential benefit of warning her partner. This is particularly true in situations where the majority of HIV positive women have been infected by their husband/only partner.

Different recommendations could be justified for the following additional reasons: in general men have the means to protect themselves from HIV infection, whereas women are often powerless to do so, due to social, economic and cultural subordination. Furthermore, male to female transmission is more efficient than female to male; women are more susceptible to infection through unprotected vaginal intercourse.

What about health professionals disclosing a person's HIV status to family or care providers?

In the interests of improving care and support for infected people, disclosure of status to individuals other than the partner certainly needs to be considered. Women in particular, may not wish to involve or inform their partner(s) at all. Experience suggests that when couples are offered testing together, the majority decline. They may however, wish to inform a close relative, friend or care provider; and in the interests of ensuring emotional and social support, this should be facilitated and encouraged. The question of shared confidentiality is receiving more attention now and will be considered in the UNAIDS and WHO review of all reporting issues. In high prevalence areas, where the majority of women have been infected by their only partner/husband, there have been calls for such disclosure by health professionals as a means of protecting women.

Does notification of AIDS (rather than HIV serostatus) to family/community care providers enhance care or prevent transmission?

This approach has been considered in situations where it is expected that the notification of AIDS to care providers within the immediate environment of the person living with AIDS will increase the likelihood of this person's access to quality, sustained care. Such notification occurs voluntarily and on the initiative of the person living with AIDS. There is no evidence that mandatory notification by health providers, which restricts the human rights of the person living with AIDS, is more effective than voluntary notification by persons with AIDS to their family/community care providers. Nor is there any evidence that notification of AIDS has any preventive effect on transmission.

In what circumstances is partner notification acceptable?

Partner notification should take place in a supportive environment which includes:

- Voluntary counselling and testing with pre- and post-test counselling and respect for confidentiality
- Care and support, including education for prevention, for the partner
- Ongoing, long term medical and psychosocial support to ensure that people living with HIV/AIDS are cared for at all stages of infection and illness
- Protection against physical harm such as violence, abuse, abandonment
- Protection, including legal measures, against social and economic harm, such as loss of income, eviction from house/shelter, discrimination in employment or insurance cover.

Can notification by health care professionals without explicit consent be justified in some circumstances?

The United Nations High Commission for Human Rights and UNAIDS have issued guidelines which clearly define the conditions which must be met for notification without explicit consent (OHCHR and UNAIDS, 1998). The guidelines state that:

"Public health legislation should authorize, but not require, that health care professionals decide, on the basis of each individual case and ethical considerations, whether to inform their patients' sexual partners of the HIV status of their patient. Such a decision should only be made in accordance with the following criteria:

- The HIV positive person in question has been thoroughly counselled
- Counselling of the HIV positive person has failed to achieve appropriate behavioural changes
- The HIV positive person has refused to notify or consent to the notification of his/her partner(s)
- A real risk of HIV transmission to the partner(s) exists

- The HIV positive person is given reasonable advance notice
- The identity of the HIV-positive person is concealed from the partner(s) if this is possible in practice
- Follow up is provided to ensure support to those involved as necessary."

Is partner notification cost effective?

The cost effectiveness of partner notification, through provider or patient referral, is not known. However experience with sexually transmitted infections shows that the procedures for provider referral are extremely labour intensive and costly, for rather low returns. Simple measures such as providing patients with contact slips (patient referral) for their partners are inexpensive and effective in some settings.

Don't people have the right to be warned about known risks to their health? Isn't it a human right to have access to information in relation to one's own health?

Yes, they do have the right to be warned and to be informed. And every effort must be made to ensure that people at risk are warned, informed and protected. The best way to do this is through voluntary counselling of the source patient so that negative consequences – in terms of public health and individual interest - are avoided.

Policy and practice must ensure the rights of those infected and the rights of those to be informed. The creation of a good social environment in which people can safely inform their partners is the eventual aim.

This is why voluntary counselling and testing is the starting point for dealing with the issue of disclosure – as it is for all HIV/AIDS prevention and care activities. VCT sites need to be set up in all parts of the world so that all those in need have access to this essential service.

The importance of public education for prevention and promotion of safer sex including condoms, cannot be overstated in relation to this problem so that more people are able to take responsibility and protect themselves.

If a doctor does not inform a partner, isn't this non-assistance to a person in danger?

Doctors do have a duty to ensure that partners are notified that they have been exposed. But this duty is to be fulfilled by health professionals in consultation with the HIV infected individual ***when all other avenues have been explored***. The OHCHR and UNAIDS guidelines (referred to and quoted in full above), clearly define the procedures and circumstances for such action.

Isn't it more important to warn the partners of HIV-positive people that they are in danger of infection than to protect the confidentiality of the HIV-positive person?

Both of these questions are of the utmost importance. The key to addressing them *adequately* lies in understanding that both the public health interest and individual interest are served by strict adherence to human rights principles including the right to privacy. The duty to warn, the right to know, and the need to protect the family and personal relationships should also be considered.

Again, education for prevention is a key strategy for alerting people to risks - warning them of the danger of infection – and advising them on how best to protect themselves.

Do any countries have public health laws making partner notification of HIV/AIDS mandatory?

UNAIDS and WHO are conducting a review of laws and policies relating to reporting and notification issues, their practical implications and their impact on individuals and societies (*see below*).

What should governments do to optimize their policies, laws and practices related to HIV/AIDS?

Before drafting policies or laws on HIV/AIDS, or on other health issues for that matter, governments should collect and analyze information needed to respond to the following questions:

1. What is the intended purpose of the new measures?
2. In what ways are the new measures likely to impact positively on public health?
3. Do the new measures appear to necessitate the restriction of human rights?

4. If so, what will it take to meet the set criteria/pre-conditions to restricting human rights?
5. Are health and other relevant structures and services capable of implementing the new measures and if not, what resources are being/will be mobilized to achieve implementation?
6. What system of monitoring, evaluation, accountability and redress will be put in place to ensure that the public health measure and, if applicable, the related human rights restrictions are achieving or progressing towards the intended effect, and that there is a process of redress when policies and laws have produced adverse effects?

Governments should review existing data and undertake their own assessment of the validity, applicability and soundness of proposed new policies and laws, with particular attention to the practical implications of such policies and laws from international legal, logistic, financial and political perspectives.

What can WHO do to help government in this regard?

UNAIDS and WHO have achieved substantial progress on a global review of the purposes, implications, application and impact of policies and laws on voluntary and mandatory, named HIV and/or AIDS reporting as well as on disclosure of HIV status, or AIDS condition, to sexual partners, family members and care providers. This review of available evidence is intended to feed the current debate on the development of new policies and laws (or the application of existing, dormant ones) based on past experience and the body of literature.

The objectives of the review are, both in a selected panel of nations, states, provinces in Western Europe, Oceania and North America, and in a panel of developing countries :

(1) To document the ***state of laws and practices*** on

- (a) reporting of HIV and AIDS through health services (by name, unique identifier, or anonymous);
- (b) public disclosure of HIV status (to employers, education services, health services, media etc.);
- (c) notification of HIV status to sexual partner(s), family members, care providers or others;
- (d) protection of confidential personal data;
- (e) systems of redress.

(2) To review the ***impact*** of the above measures on:

- (a) protection of privacy
- (b) discrimination, or absence thereof, towards individuals with HIV, their sexual partners, their community
- (c) public health impact such as time interval between presumed onset of HIV infection and initial reporting
- (d) access and compliance to HIV treatment, and discrimination within the health care setting
- (e) social status (e.g. normalization of HIV/AIDS in society, partner relations, access to employment, housing, insurance).

The tangible outcome of this review will be to inform national policy decision on HIV/AIDS named reporting and partner notification not only by providing evidence of whether or not it has been found safe and effective, but also to determine what systems, skills and safeguard mechanisms should be in place for such policies and laws to be both safe and effective.

Is it not up to governments to decide what policies and laws best respond to their needs?

In making their decisions, governments have the obligation to respect, protect and fulfill human rights under international human rights law. Governments are also responsible for protecting and promoting public health. Thus, governments have the responsibility to enact and implement policies and laws that comply with human rights and sound public health principles. Under the United Nations Charter, WHO--as a UN Agency-- has the responsibility to support Member States in fulfilling their obligations to health and to human rights. As a UN institution, WHO cannot advocate or support policies that would not be respectful of human rights.

Definition of terms

Reporting is the procedure through which health providers systematically inform health authorities of each individual case of HIV infection and/or AIDS presenting in consultation, or in some cases, known to them.

Named reporting: The names and addresses of individuals with HIV infection and/or AIDS are provided. The information is intended only for the health system.

Unnamed reporting: Names and addresses of individuals are removed and health authorities are provided only with information on numbers of cases presenting or known at health centre or laboratory. When possible, an identifying code is used in order to avoid duplication (reporting as separate cases of HIV infection and/or AIDS each time the same individual presents for care).

Partner notification (also known as contact tracing) is the process of contacting the sexual partners of an individual with a sexually transmitted infection including HIV, and advising them 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 for counselling, testing and other prevention and treatment services.

One of the fundamental tenets of partner notification is that confidentiality of the source partner is maintained absolutely.

Partner notification can be done by the patient him or herself, by the health provider or through combined efforts of both.

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

Provider referral: The health care workers involved in the index patients' care can notify the sexual partners without naming the patient concerned.

Conditional referral: The health care worker of the index cases obtains names of their sexual partner but allows patients a period of time to notify partners themselves. If the partners are not notified within this time period, the health care professional notifies their sexual partner without naming the patient concerned.

Disclosure refers to the act of informing any individual or organization (a health authority, an employer, a school, for example), of the serostatus of an infected person, or 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.

Confidentiality refers to the patient's right to expect that health care professionals will not disclose personal health information without the person's consent. The right to confidentiality embraces intimate matters, such as sexual relationships, illicit drug use, and health status, that a patient might discuss with a health care professional.

"Right to Confidentiality" derived from the right to privacy, reflected in several human rights documents in particular, Article 17 of the International Covenant on Civil and Political Rights provides that " No person shall be subjected to arbitrary or unlawful interference with his privacy, family, 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."

In the context of HIV/AIDS, the right to privacy encompasses the obligation to protect physical privacy, to seek consent for the disclosure of HIV status and to protect privacy of information including the need to respect confidentiality of all information relating to the person's HIV status.

The duty of States to protect the right to privacy therefore includes the obligation to guarantee confidentiality.

Public health surveillance is the collection of information of sufficient accuracy and completeness regarding the distribution and spread of infection to be pertinent to the design, implementation, or monitoring of prevention and control programmes and activities.

Unlinked anonymous screening is the testing of specimens for markers of infection after elimination (unlinking) of all identifying information from each specimen.

Sentinel serosurveillance for HIV infection involves the routine testing of a predetermined number of persons at specific sites and within specific population groups. Testing is performed on blood samples that have been collected for other purposes (eg for blood donation or for measuring haemoglobin in antenatal care), in a regular and consistent way, either daily, monthly or quarterly. The main purpose is to detect changes and to monitor trends. Sentinel populations need not be "representative". Testing is unlinked and anonymous and there is no need for individual informed consent.

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