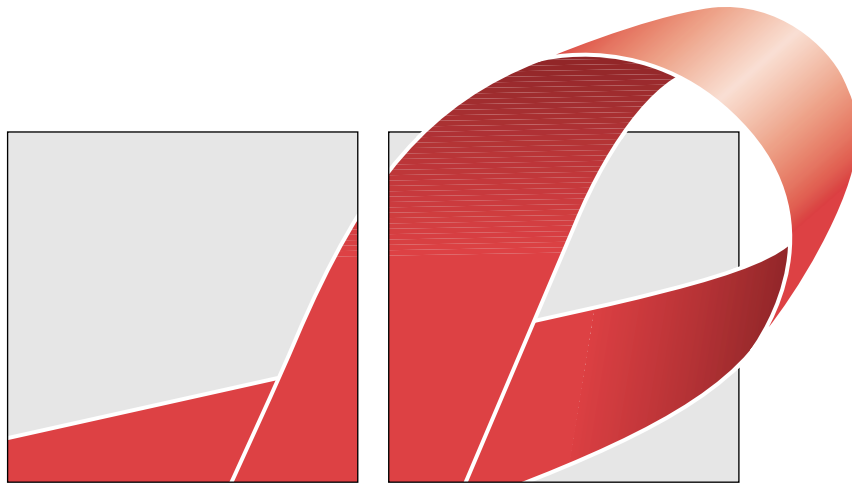


Protocol for the identification of discrimination against people living with HIV



Joint United Nations Programme on HIV/AIDS
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Protocol for the identification of discrimination against people living with HIV

1. Introduction

One of the objectives of National AIDS Programmes (NAPs) is to reduce the personal and social impact of HIV infection, including discrimination against those living with or suspected of having HIV/AIDS. This Protocol seeks to further that objective by providing a tool for measuring arbitrary discrimination in a range of key areas in everyday life.

The Protocol is aimed at National AIDS Programmes, but it is not just for them. It may also be used by others – interested organizations, groups or persons, including those living with or affected by HIV/AIDS – in order to detect arbitrary discrimination. Indeed, a broader range of users will help in making the Protocol a more effective human rights tool.

The Protocol is not intended to be used only for the detection of discrimination, but also to encourage the adoption and enforcement of measures against such discrimination, as well as the dissemination of good practice measures.

Why have a Protocol on the identification of arbitrary discrimination on the grounds of HIV/AIDS status, actual or presumed?¹

This Protocol has been designed for two reasons:

1. The identification of different forms of arbitrary discrimination, with a view to eliminating them, helps to respect, fulfil and protect human rights. This is an important goal in its own right, as recognized by the ongoing attention and deep commitment to human rights across national and international communities.
2. Identification and elimination of arbitrary discrimination is an imperative in the control of HIV/AIDS. In this field, public health and human rights do not conflict with each other: instead, public health interests provide an additional and compelling justification for identifying and eliminating arbitrary discrimination on the grounds of HIV/AIDS status.

Human rights, non-discrimination and HIV/AIDS

Non-discrimination has been recognized as a core human right, one that is essential to ensuring human development, well-being and dignity. As a result, provisions on human rights codified in various national constitutions and laws prohibit discrimination. It is also prohibited by a range of exist-

¹ References throughout the text to HIV/AIDS status (or to persons living with HIV/AIDS) should be taken to be 'actual or presumed' though this expression is not repeated.

ing international instruments, including the Universal Declaration of Human Rights; the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights; the International Convention on the Elimination of all Forms of Racial Discrimination; the Convention on the Elimination of all Forms of Discrimination against Women; and the Convention on the Rights of the Child. In addition, regional instruments, namely the African Charter on Human and Peoples' Rights, the American Convention on Human Rights, and the European Convention on Human Rights and Fundamental Freedoms, prohibit discrimination. Finally, several of the conventions and recommendations of the International Labour Organization call for steps to be taken against work-related discrimination.

Since 1990, the United Nations Commission on Human Rights has also adopted a series of resolutions on human rights and HIV/AIDS. These resolutions confirm that discrimination on the basis of HIV/AIDS status is prohibited by existing international human rights standards. They also clarify that the term 'or other status' used in the general non-discrimination clauses of international and regional human rights instruments (such as the International Covenant on Civil and Political Rights) 'should be interpreted to include health status, such as HIV/AIDS'.

Thus, there is now an international consensus on identifying and eliminating arbitrary discrimination on the grounds of HIV/AIDS status. Moreover, the rights codified in the above international and regional instruments may be violated by measures involving arbitrary discrimination on the grounds of HIV/AIDS, and in the case of some of them, non-compliance can, if proved, lead to sanctions against the States responsible. A number of the international treaties, including the International Covenant on Civil and Political Rights, also require participating States to submit periodic country reports to their monitoring committee and, after review of the report, to appear at a face-to-face session with the committee. Following this exercise, the United Nations will publish the committee's 'Concluding Observations and Recommendations'. Several of these committees allow nongovernmental organizations (NGOs) to submit 'shadow' country reports, providing HIV/AIDS organizations with an opportunity to bring evidence of arbitrary discrimination before these particular committees.

As noted above, arbitrary discrimination on the grounds of HIV/AIDS status may also be in violation of national constitutions or laws. In many States, private bodies and organizations, including a range of employers, have recognized the importance of identifying and eliminating such discrimination, even though they may not have been obliged to do so by existing national or international laws. As a result, a number of these private actors have adopted measures to combat arbitrary discrimination, e.g. codes of conduct for professional bodies, and workplace guidelines. Such measures provide crucial leadership, advocacy and action on identifying and eliminating arbitrary discrimination in civil society against people living with or suspected of having HIV/AIDS. They also counteract the general tendency towards over-reliance on law and legal reform. Designing and enforcing just laws is a crucial task, but it is one that takes a lot of time and resources, as well as strong political and social will. In addition, many legal systems are not easily accessed by marginalized groups.

Public health, non-discrimination and HIV/AIDS

The identification of different forms of arbitrary discrimination, with a view to eliminating them, not only helps to protect human rights, it is also an imperative in the control of HIV/AIDS. In other words, arbitrary discrimination against people living with or suspected of having HIV/AIDS is not just wrong and unjust, it is also ineffective as a public health measure.

Arbitrary discrimination against people living with HIV/AIDS, or suspected of it, can have three devastating public health consequences:

1. Arbitrary discrimination tends to instil fear and intolerance. It creates a climate that interferes with effective prevention by discouraging individuals from coming forward for testing and from seeking information on how to protect themselves and others, thus deepening the adverse impact of living with HIV/AIDS. Since the effectiveness of a prevention policy depends on reaching those who are at risk and encouraging them to adopt safe behaviour, it is essential to combat the discrimination that drives people away from these programmes.
2. Arbitrary discrimination may engender a dangerous complacency in individuals and groups who are not targeted and therefore assume that they are not at risk. For example, if a State treats HIV/AIDS as a problem related to foreigners visiting or resident in the country, it may increase the vulnerability of its own citizens.
3. Arbitrary discrimination against people living with HIV/AIDS, or suspected of it, tends to exacerbate existing forms of marginalization, such as racism, gender-based discrimination, homelessness, and discrimination against children. It deepens the already-increased vulnerability of marginalized groups to HIV infection, and obstructs their ability to deal with the impact of their own infection and/or infection in their family or associates.

Discrimination against people living with HIV/AIDS, or suspected of it, also extends to those with whom HIV/AIDS is associated in the public mind. This group includes people having same sex relationships, sex workers, injecting drug users, haemophiliacs, and family members and associates of people with HIV/AIDS. Reducing discrimination against these groups as a whole is in itself an important public health measure in terms of creating a supportive environment, thereby encouraging personal responsibility and protective behaviour. It is also, of course, important to the dignity, human development and well-being of the individuals concerned.

The particularities of HIV/AIDS must determine the nature of the strategy necessary to control this disease, based principally on prevention, and promotion of personal responsibility, as well as on care and health support. Coercive or punitive approaches aimed at identification and/or compulsory treatment of all people with HIV/AIDS, or suspected of it, do not work: basically, people, including those most at risk, will not come forward if they fear discrimination. Arbitrary discrimination is therefore wrong, unjust *and* ineffective.

Experts and many national and international authorities, including WHO, UNAIDS, and the Council of Europe, agree that the particularities of HIV/AIDS – especially the fact that it is not contagious in everyday life, its period of latency is long and there is no cure – mean that it is only in very rare circumstances, and even then only by fulfilling a number of criteria (see Section 2.2), that the imposition of certain limits on individual rights can be justified.

2. Definition of Arbitrary Discrimination

2.1 Basic concepts

In general terms, discrimination refers to any form of distinction, exclusion or restriction affecting a person, usually, but not only, by virtue of an inherent personal characteristic, irrespective of whether or not there is any justification for these measures.

The legal concept of discrimination differs from this general one. It takes account of the justification – in terms of purpose, proportionality and effects – of any differences in treatment between people. Thus, not all differences of treatment are necessarily discriminatory: differences based on reasonable and objective criteria may be permissible.

This Protocol follows the legal concept of discrimination. It is aimed at identifying and eliminating **arbitrary discrimination**, a concept defined by analogy with general guarantees of non-discrimination in a range of important international instruments. These include the International Covenant on Civil and Political Rights; the International Convention on the Elimination of all Forms of Racial Discrimination; and the Convention on the Elimination of all Forms of Discrimination against Women.

The Protocol provides a tool for drawing up a list of types of arbitrary discrimination using an inductive methodology. It is hoped that this will help National AIDS Programmes and others to identify and monitor arbitrary discrimination. The Protocol also aims to provide a platform for implementing legal and other interventions to eliminate arbitrary discrimination, as well as a mechanism whereby examples of good practice – whether by public authorities or private institutional actors – can be collated for wider dissemination.

For the purposes of this Protocol, arbitrary discrimination is defined as follows:

Any measure entailing an arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health.

The existence of arbitrary discrimination is to be assessed by taking various criteria into account. These criteria are set out in Section 2.2 below.

2.2 Criteria for assessing the existence of arbitrary discrimination

1. The principle of non-discrimination requires that **all persons in similar situations should be treated in an equal manner**.
2. Arbitrary discrimination may be the result of an **action** or an **omission**. It may also be **intentional** or **unintentional** (occasionally, it may be the unexpected result of good intentions). Furthermore, arbitrary discrimination may occur where **HIV/AIDS is only one of several reasons for a particular measure**. It may also be **direct** (where the discrimination is explicitly based on characteristics of, or attributed to, the affected individual(s)) or **indirect**

(where a practice, rule, requirement, or condition is neutral on its face but has the effect of discriminating against particular groups who cannot, or are less able to, comply with the rules). However, this formal distinction is less important than a practical result-orientated approach.

3. **Rights to non-discrimination can be justifiably restricted in certain narrowly defined circumstances in the interests of a limited number of overriding goals** (e.g. restricting donation of blood by those who have been confirmed HIV-positive or who have recently returned from a high-prevalence area).¹ But **simply justifying a discriminatory measure as necessary for public health** – as is often done in the context of HIV/AIDS – **is not sufficient**. For a measure restricting the rights to non-discrimination of people living with or suspected of having HIV/AIDS to be justifiable, two important criteria have to be met: ²

a) The measure must be in the interest of a **legitimate objective**. International human rights law provides that public health, the rights of others, morality, public order, and national security are all examples of legitimate objectives.

b) In assessing the measure, its objective or purpose should be taken into consideration – which, in this instance, is usually to safeguard public health – bearing in mind the limited range of modes of transmission of the virus (sexual, through blood, and from mother to child). Thus, for example, it may be legitimate to impose an HIV test on blood donations or to exclude people exhibiting ‘risk behaviour’ from blood donation in view of the risks inherent in blood transfusions. On the other hand, and for the same reasons, it is not legitimate to impose generalized screening at recruitment for work or in the workplace. Similarly, while communication by doctors to the authorities of the number of people with HIV/AIDS, in a strictly anonymous manner and on the basis of voluntary tests, for the purpose of establishing statistics may be legitimate, communication of this information to the Ministry of Health without regard for anonymity and informed consent is not.

Even when a measure is for a legitimate objective, **the means employed to achieve it must be proportionate to the aim pursued**. They should constitute **the least restrictive means available**. Appreciation of whether the means are in proportion to the aim pursued also requires consideration of **the effectiveness of the measure in attaining the objective sought**. Thus, to take an extreme example, tattooing of people with HIV/AIDS to try to prevent the spread of the epidemic is a measure out of proportion to the aim pursued. Similarly, police round-ups and mandatory testing of sex workers is a disproportionate measure.

In general, a measure that stigmatizes people with HIV/AIDS will not be effective in relation to pursuit of the objective of safeguarding public health. The effectiveness of a measure will most often depend on the characteristics of the epidemic of the virus

¹ Under international human rights law, some rights – including the right to life and freedom from torture – cannot be restricted under any circumstances.

² Where a restriction is State-imposed, international human rights law requires an additional, third criterion to be met: the restriction must be provided for and carried out in accordance with law. This means that the restriction must be according to specific legislation, which is clear, precise and accessible, in order that it is reasonably foreseeable that individuals will regulate their conduct in accordance therewith.

(including, in particular, its limited modes of transmission). Thus, measures that totally or largely fail to take account of the medical facts about HIV/AIDS will generally be impugned as discriminatory.

Application of these criteria can help to reveal measures of arbitrary discrimination in many areas of social life, including those that fall outside State responsibility under international human rights law and/or are outside the reach of national law (e.g. because they occur in an area of the private sector that is outside the control of public authorities).

2.3 Sources of arbitrary discrimination

People with HIV/AIDS face many forms of arbitrary discrimination. Some forms are obvious or crude (e.g. physical violence, or refusal of a particular service). Others may be difficult to detect (e.g. a measure may not mention HIV/AIDS but may effectively be aimed at groups associated with the epidemic in the public's mind,¹ or a measure may unintentionally have the effect of arbitrarily discriminating on the grounds of HIV/AIDS²).

Certain forms of arbitrary discrimination may affect only specific groups. Moreover, forms of arbitrary discrimination are not static: they may change with shifts in the nature of the pandemic or a particular State's response to it. In addition, people with HIV/AIDS may experience 'anticipated discrimination' or 'felt stigma' as well as actual arbitrary discrimination (e.g. they may limit their own care-seeking behaviour because they fear or suspect discrimination).

This Protocol does not set out to examine all forms of arbitrary discrimination. In particular, it omits consideration of such discrimination in certain private relations, including within the family and between friends or acquaintances. This omission should not be taken to imply that such instances of arbitrary discrimination are not of paramount importance for persons living with HIV/AIDS or that they merit less attention by policy-makers.

The Protocol focuses on **institutional discrimination**, examining three sources of possible arbitrary discrimination:

- law;
- the internal regulations and procedures of public and private bodies, organizations or groups;
- occurring in practice, for which there is no written basis (e.g. there is no law, regulation or procedure, or the arbitrary discrimination is occurring despite the existence of a law, regulation or procedure that purports to prohibit it).

¹ This is sometimes described as discrimination related to HIV/AIDS.

² Investigators will have to be particularly alert to those forms of arbitrary discrimination that are difficult to detect. Thus, they will need to remember that arbitrary discrimination on the grounds of HIV/AIDS is not always evident on the face of a law, internal regulation or procedure, or a practice. For example, a measure may not mention HIV or AIDS and yet may effectively be aimed at persons suspected of HIV/AIDS (e.g. measures of health control imposed on prostitutes on the basis that they are or may be persons at risk).

These three sources of possible arbitrary discrimination are wide-ranging. They were chosen on the basis that they would contribute to the Protocol's primary aim of National AIDS Programmes with a usable tool for the identification, monitoring and elimination of arbitrary discrimination on the grounds of HIV/AIDS status.

By focusing on these three sources, the Protocol covers circumstances where arbitrary discrimination is legal (e.g. where there is a national law that purports to justify it), as well as those where it is illegal. The use of these three sources also permits examination of forms of arbitrary discrimination that fall outside the reach of national and international law (e.g. where such discrimination occurs in an area of the private sector that is not regulated by public authorities, or where it does not appear to fit within the current doctrine of State responsibility in international human rights law).

The Protocol aims to identify discriminatory practices, as well as examples of such discrimination in laws and internal regulations or procedures. Identifying arbitrarily discriminatory practices is a difficult task. However, it is a vital and urgent task if human rights and public health goals are to be met. There are two reasons for this difficulty: first, neither legal rules nor internal institutional regulations or procedures are always fully respected; and secondly, as noted above, there may be no applicable legal rule, or internal regulation or procedure.

3. Definition and Measurement of the Indicator

3.1 Fields covered

The Protocol targets arbitrary discrimination in a wide, but non-exhaustive, range of fields. The method used has been to draw up a list of 37 different situations in ten major areas of social life in which distinctions, exclusions or restrictions against persons with HIV/AIDS may occur (see Annex 1).

The ten major areas of social life are as follows:

- I. Health care
- II. Employment
- III. Justice/legal process
- IV. Administration
- V. Social welfare
- VI. Housing
- VII. Education
- VIII. Reproductive and family life
- IX. Insurance and other financial services
- X. Access to other public accommodations or services (e.g. funeral services)

¹ Total number of practices/rules that may be arbitrarily discriminatory in relation to HIV/AIDS.

In each area, only the most common types of discrimination have been listed. This does not in any way preclude the existence of other arbitrarily discriminatory situations, or the need to combat them.

3.2 Proposed Indicator

$$\frac{\text{Number of non-discriminatory practices/rules identified}}{37} \times 100$$

The proposed Indicator is a positive one: it generates a percentage identifying **the degree of non-discrimination** in the fields covered by this Protocol.

For the purposes of this Indicator, the total number of practices/rules that may be arbitrarily discriminatory in relation to people living with HIV/AIDS has been fixed at 37.

The Indicator gives equal weight to each of the 37 situations of potential arbitrary discrimination selected for investigation. This means that it does not take account of their relative frequency, or of the intensity of the suffering caused. However, users of the Protocol may wish to disaggregate data in these ways for purposes of report and further action after completing measurement of the Indicator itself.

The Indicator's reference to 'rules' includes both laws (e.g. constitutions, legislation, judge-made law, and traditional or customary laws) and internal institutional regulations and procedures.

The question of whether practices and/or rules are arbitrarily or non-arbitrarily discriminatory should be established in accordance with the criteria outlined in Section 2.2 above, including the need for measures to be in pursuit of a legitimate objective and for the means employed to be proportionate to the end pursued.

3.3 Measurement of the Indicator

The list at Annex 1 of this Protocol provides the key tool for measurement of the Indicator. The measurement should proceed in four stages:

Stage 1

For each situation, it should be established whether the potential arbitrary discrimination is present in law, and/or in internal regulations and procedural documents, and/or in practices for which there is no written basis.

An exact reference to a particular law, and/or internal regulations and procedures, and/or an unwritten practice should be specified for each and every instance of potential arbitrary discrimination. Annex 2 has been designed to facilitate such record-keeping.

Annex 2 requires the following information:

For law

The number of the article/section etc. and the name of the law in question (or the name of the case etc.), together with the exact wording, where applicable, to enable the measure in question to be found in the national law.

For internal regulations or procedures

To what institution, association, group, etc. do the regulations and procedures in question belong, and what is the exact wording of their text?

When regulations or procedures emanate from a private body that does not wish such internal data to be known, care should be taken to ensure that the data are not directly identifiable (see Section 4.9 on confidentiality and data protection).

For practices where there is no written basis

Aim to provide as detailed an account as possible without jeopardizing confidentiality (again, see Section 4.9).

Stage 2

Aim to verify all information received (see Section 4.6).

Stage 3

Once verification is as complete as possible, examine each recorded situation in order to decide whether it can be classed as *arbitrary* in accordance with the criteria set down in Section 2.2 of this Protocol.

Stage 4

Using Annex 1, record those situations which have been classified as arbitrarily discriminatory *and* which fall within the list as set out at Annex 1. Do not add further situations to Annex 1, as this will compromise measurement of the Indicator.

Measurement of the Indicator can proceed once all relevant situations have been recorded on Annex 1.

Annex 1 contains a table made up of two main columns. These two columns are divided into three subcolumns and a varying number of rows. Each row represents one of the 37 measures of potential arbitrary discrimination. The three subcolumns identify the three sources of arbitrary discrimination covered by this Protocol. They allow for answers to the question as to whether a particular restriction, distinction or exclusion is provided by:

- state laws (e.g. constitution, legislation, judge-made law or traditional or customary law) or, if the country is divided into different entities, by laws in any one of them; and/or
- internal regulations and procedures of public or private bodies, organizations or groups; and/or
- occurring in practice.

A cross should be placed in one, two or three of the columns for one of the 37 situations of potential arbitrary discrimination when it has been determined that there is evidence of such discrimination. Thus, for example, if after a first survey, 19 situations out of the 37 on the list are found to be non-discriminatory, the Indicator will be $19/37 \times 100 = 51\%$.

In addition to taking a measurement of the Indicator, investigators may choose to disaggregate the data according to sources of arbitrary discrimination (e.g. internal regulations or practices) for the purposes of report, analysis and subsequent action. Data may also be discussed and classified according to different criteria such as: most frequent forms of discrimination; who does the discriminating; and/or those acts of discrimination easiest to change.

As previously stated, Annex 1 does not reflect all the possible forms of arbitrary discrimination that may exist in a given geographical area. Investigators and coordinators are encouraged to identify, describe and record arbitrarily discriminatory measures that do not appear to fit into any of the categories in Annex 1. Annex 2 may be used for this purpose. Annex 1 should not be amended in order to include additional situations, as this would compromise measurement of the Indicator.

It should be noted that the Indicator, and the Protocol more generally, are not scientific devices. As a result, the measurement of arbitrarily discriminatory measures can only be approximate. Furthermore, a range of factors, including the quality of investigators; the time and resources available; the level of political commitment; and the attitude of opinion-leaders, may skew the scoring of the Indicator. Repeated in-depth studies over time may reduce such biases, but they cannot remove them completely.

Bias is more likely to arise in information collected in respect of internal rules and procedures and practices. For example, obtaining the texts of internal regulations and procedures of private bodies, associations or groups will depend on the good will of the directors of these establishments who may or may not agree to make them available, and on the persuasiveness of the investigators. In addition, differences may be observed, for example in the number of arbitrarily discriminatory internal regulations and procedures between different institutions; between the different areas described in the questionnaire; between different areas of the country; and between surveys repeated at regular intervals, but such differences may be apparent rather than real. One way of investigating this latter possibility might be to record the degree of difficulty encountered and the level of cooperation accorded when attempting to collect information. Annex 4 of the Protocol contains a form that has been specially designed for this purpose.

Information concerning practices will mostly be obtained through organizations concerned with people living with HIV/AIDS and through direct complaints and key informants. Publicity and a proactive approach will be required in seeking out information about arbitrarily discriminatory practices in each of the areas listed. However, even when this systematic approach is used in each area, it is likely that there will still be a certain number of differences that are apparent rather than real. Again, it may be useful for investigators to use Annex 4 in order to record the difficulties encountered and the level of cooperation accorded when attempting to collect information.

Bias may also skew attempts to identify changes in arbitrary discrimination over time. For example, each time a situation is reassessed, it may seem that there has been an improvement or a deterioration in some particular area simply because more or fewer instances have been reported from one investigation to the next, regardless of the real volume of such occurrences.

The risk and/or existence of bias does not mean that the Protocol and its Indicator cannot be used to good effect. Investigations using the Protocol will be able to identify areas in which there is arbitrary discrimination against people living with HIV/AIDS. This should enable National AIDS Programmes and other users to bring pressure to bear on the appropriate governmental agencies and private sector bodies, organizations and groups to modify and improve legislation and internal regulations and procedures. With regard to practices, it should assist them in gauging the sector(s) in which there are real problems, thereby contributing to attempts to institute appropriate remedial actions.

4. Methodology

Identifying arbitrary discrimination is a complex task that requires a good knowledge of the law and internal regulations and procedures, as well as practices. It represents a considerable investment in terms of costs and staff time.

One individual or agency heading a team will need to assume overall coordination of the survey. The cost of an individual survey should not exceed US\$ 5000.

4.1 Defining the initial baseline survey

The National AIDS Programmes (or other user) should first of all define the geographical area for the initial baseline survey.

It is recommended that a big city be used as a starting point, since a higher concentration of people living with HIV/AIDS, and the agencies concerned with them, are to be found there. It would also be useful to obtain information for the baseline survey from one regional centre. While the *number* of instances of arbitrary discrimination may be greater in a big city, individual instances of arbitrary discrimination may be more serious in a regional or rural area, or a lower HIV prevalence area. This increased adverse impact may be the result of lack of information and education about HIV/AIDS, as well as difficulties relating to confidentiality.

In order to monitor progress in the reduction of arbitrarily discriminatory practices as a result of work by national AIDS programmes and others, repeated surveys should be carried out every two to three years. For comparison, it will be necessary to return to the same locations when repeating the surveys. However, other large cities and regional centres should be added to enable extension of the evaluation nationally.

4.2 Selection and training of investigators

Each time a survey is conducted, an entity (either an individual or an agency) should be put in charge of the initial orientation programme, collection of data, effective distribution of tasks, and overall coordination of the work. It is important that the coordinator design a well-planned orientation programme. The coordinator must also play an active part throughout the survey, including sitting in on a representative sample of the interviews conducted by each investigation subgroup; promoting consistency of interpretation and practice as regards data collection and verification, and cross-checking of information; providing a final check on anonymity, confidentiality and data protection; and taking a lead in the determination of whether arbitrary discrimination exists.

A survey will probably require a team of six to ten investigators (men and women) for a duration of four to six weeks. The aim should be to bring together lawyers, NGO representatives, social workers, government officials, and others with the necessary expertise to undertake the complex task of gathering information on possible arbitrary discrimination in the ten key areas, and to evaluate that information by testing the evidence.

Investigators should be assigned responsibility for one or more of the ten key areas included in Annex 1 based on their expertise. There may be some overlap between areas: for example, Annex 1's Employment section will need to be used by investigation subgroups other than the specialist Employment one (e.g. the Health Care, Administration (in relation to the civil, military and police services), and Education subgroups).

For the collection of information on laws, policies and practices, the investigators should not only include officials employed by the government administration, but also members of associations or organizations directly concerned with, and/or involving, people living with HIV/AIDS or regarded as at risk of infection. Such groups, through the experience of their members, are undoubtedly best placed to detect problems, especially the practical aspects of these.

The purpose of the work must be explained to the investigators. They should also be familiar with the most important characteristics of the HIV/AIDS pandemic. They must be educated about and sensitive to the issues involved, including concerns about anonymity, confidentiality and the informed consent of those participating. It will be necessary to provide the investigators with two or three days training before commencing the survey. A detailed orientation programme is provided in Annex 6.

The orientation programme should provide background briefing on human rights and public health issues in relation to HIV/AIDS. Background materials on the basic concepts of human rights and public health could usefully be provided (e.g. the Protocol itself and extracts from other relevant and useful texts including *AIDS, Health and Human Rights: An Explanatory Manual*),¹ and discussion of case-studies and role-plays may provide valuable opportunities for troubleshooting.

The orientation programme should ensure that each investigator understands the purposes of the Protocol; the methods and challenges of data collection, including interviewing skills; the definition of arbitrary discrimination; and the need to verify, weigh and evaluate the evidence

¹ International Red Cross and the François-Xavier Bagnoud Centre, 1995.

of potential arbitrary discrimination. It is also crucial that each investigator appreciates the need for confidentiality and data protection.

A further overall aim of the orientation programme should be to promote consistency of interpretation and practice across the investigation teams.

Investigators should also be informed about their payment, subsistence and travel arrangements during the orientation programme.

4.3 Follow-up investigators' meetings

The entire team of investigators will need to meet on at least two occasions following the initial orientation programme. Additional review meetings between the coordinator and individual investigation subgroups should also be organized if possible. Such additional meetings will allow evidence to be sifted, assessed and challenged as the survey progresses, enabling investigation subgroups to search for further supporting evidence when necessary. These additional meetings can help the entire team to build towards the second meeting (see below) when properly detailed cases can be presented for final assessment and classification.

First meeting

A first meeting of all investigators should be organized after two weeks of fieldwork. This meeting has three purposes:

1. It should be used to check on progress.
2. It should be used to maintain consistency, direction and purpose in the survey.
3. It should be used to review problems encountered and unforeseen obstacles in the data collection and collation.

The concept of Lot Quality Assurance (LQA) is recommended in order to facilitate the investigation and enable the team to quickly refocus its attention on those areas where arbitrary discrimination may be occurring. Each group of investigators should report their early findings on areas where evidence of arbitrary discrimination is sought. If there is corroboration by the other groups that no instances of potential arbitrary discrimination were found in a particular area, the area may be classified as non-discriminatory. However, if there are some indications that a particular area may be problematic, further investigations should be carried out.

Second meeting

A further meeting of the investigators should be held at the end of the second wave of investigations. The National AIDS Programme Manager should be present at this meeting. The second meeting has three purposes:

1. It should be used to check that the best possible effort has been made to verify each recorded situation of potential arbitrary discrimination.
2. It should be used to examine each recorded situation of potentially arbitrary discrimina-

tion in order to determine (a) whether the situation can be classified as arbitrarily discriminatory in accordance with the criteria in Section 2.2, and (b) following a positive classification, whether it can be recorded on Annex 1 as an example of one of the 37 situations listed there.

3. It should be used to check that all information collected or handled during the investigation has been rendered unidentifiable. If any elements of identification remain, they must be removed.

4.4 Selection of respondents in key areas

The survey will rely on direct witnesses and key informants as respondents. A preliminary list of respondents should be drawn up by the National AIDS Programme, or other user, and presented to the investigators during their training period. This list will provide a basis for the allocation of tasks to individual investigators who should then identify and make appointments with the appropriate key respondents in their designated areas.

The investigators may be able to gather vital information from direct witness accounts. In addition, however, it is proposed that information should be systematically gathered in the ten areas identified in Annex 1 from persons with special knowledge of each of these areas. Such persons are described as key informants in this Protocol.

Key informants will include doctors, nurses and paramedical personnel, and social workers as well as teachers and lawyers. In most countries, it should be possible to ask certain key informants to keep a record of instances of potential arbitrary discrimination experienced by people living with HIV/AIDS whom they encounter (e.g. among their patients or clients), until a sample of at least 150 persons is reached. Since such data may be damaging to individuals, it should be stored and transmitted in ways that protect individuals' privacy. Ways of recording and storing such information which minimize the likelihood of individuals being identified (e.g. use of coded numbers, pseudonyms, etc.) should be explored and implemented.

4.5 Collection of data

For some of the areas on the list in Annex 1, there may be no evidence of discrimination. However, this does not necessarily mean that there is none. A systematic, even if summary, investigation of each of the sectors listed should therefore be carried out. If no legal texts or regulations reveal potential arbitrary discrimination in access to social welfare or housing, for example, and none is reported, it may nevertheless be occurring in practice. Information should be sought actively.

The collection of data involves sharing of tasks and the use of preliminary questionnaires to gather baseline information. These questionnaires should be given to all investigators and, generally, to all the persons responsible for the collection of information. They could also be given to some of the people or organizations who play an active role in the sectors in question (e.g. doctors, private companies, etc.). A very simple model of a questionnaire, including a checklist of topics to be covered is provided in Annex 3.

Investigation subgroups should each be responsible for taking the lead in key areas, i.e. the legal subgroup will have responsibility for reviewing the law, finding legal texts relevant to discrimination and pertinent case-law. The legal subgroup should also lead on some aspects of the criminal justice system. Other obvious investigation assignments include social workers concentrating on social welfare, housing and education, and NGOs on employment, police administration, insurance, and contacting people with HIV/AIDS or regarded as at risk thereof. Similarly, the health care specialists can focus on health issues.

There may be some overlap between areas. For example, as noted above, a range of investigation subgroups, including Health Care, Administration and Education, will need to collect data on potential arbitrary discrimination in employment in their particular fields. The data collected can then be fed into the specialist Employment subgroup.

The recommendations and directives given to investigation subgroups and individual investigators will depend on the kind of research that the subgroup or person in question is required to carry out. Some examples are described below.

□ For law

Research on national law should be relatively straightforward. It will require access to key sources, which may be compendia of laws or official publications containing legal texts, and sometimes regulations. These are public documents and they should permit clear answers to the questions asked about potential arbitrary discrimination.

A systematic review of laws (e.g. the constitution, legislation, judge-made law, and customary law) relating to the ten areas covered in Annex 1 should be carried out. This should be done on the basis of existing written information, and discussion with jurists or people with knowledge of the domain.

People with HIV/AIDS may be deterred from using the law to seek protection from arbitrary discrimination, or redress for harm they may have suffered, because they fear that this course of action would expose them to publicity (resulting in loss of privacy), may take too long, and may be financially or emotionally difficult. The legal investigators should collect data from agencies (e.g. advice and welfare agencies) on cases where individuals had a prima facie case in law but decided not to take action. Case-law and prosecution policy should be examined for instances of bias in prosecution and/or judgment. Sentencing policy should also be examined.

□ For internal regulations and procedures

Research on internal regulations and procedures poses greater difficulties. It may not be easy to find out which bodies, organizations or associations have adopted internal regulations and procedures that could be arbitrarily discriminatory. The approach adopted in the public and private sectors will need to be different, and it will be important for the investigation subgroups to enlist the help of key informants.

For the public sector, each department (corresponding to the areas listed in Annex 1) could be asked to supply information on the internal regulations and procedures in the public institutions under its authority. Written documents referring explicitly or implicitly to any HIV/AIDS-related

measure should be sent to the investigators. Access may be easier if the survey has some form of government support.

For the private sector, the investigation subgroups will need to approach a certain number of large, medium and small bodies, organizations and associations (e.g. corporate, professional, etc.) in different areas, and ask them for copies of their written regulations and procedures. This task should be carried out through the agencies that work directly with people living with HIV/AIDS. Trade unions, or trade and professional organizations, may be able to supply valuable information on the private sector.

Private sector bodies, organizations and associations may be defensive about such enquiries, not least because many will not have policies in place to prevent arbitrary discrimination. It may be useful to invite such parties to help the investigation teams in their overall task of suggesting what changes would be likely to help eliminate forms of arbitrary discrimination in their particular setting. Some private sector entities may agree to respond to an anonymous questionnaire.

In the event of non-cooperation, it will be necessary to proceed through other channels. It is the decision of the investigation team as to which alternative sources of information should be accessed. Possible sources include employees, unions, service users, and association members. Due care should be taken to ensure that these sources are kept anonymous and confidential, so that they are not exposed to any adverse consequences.

□ For practices

Data collection on practices may pose the most severe problems for the investigation team. One approach would be to put out regular information campaigns in the media (press, radio or television) to let citizens know that efforts are being made to combat arbitrary discrimination on the grounds of HIV/AIDS status. These campaigns should invite any individuals who feel they have been the victims of arbitrary discrimination to get in contact with certain agencies (specifying the names of contacts in the agencies) in order to help combat these forms of discrimination. Emphasis should be placed on the fact that any such information would be given in strict anonymity. This guarantee may encourage people other than those who would come forward spontaneously to report their experiences.

Existing human rights bodies (NGOs, ombudspersons, etc.), HIV/AIDS service organizations, legal service groups, and those in legal and ethical networks may be best placed to carry out the investigation of potential practices of arbitrary discrimination. For example, an investigator from one of these agencies may inspire more confidence in victims of arbitrary discrimination than an investigator who is in some way connected with the public authorities.

4.6 Verification of information

Verification of accounts of potential arbitrary discrimination is crucial. Verification using a range of sources should be completed to the best extent possible. The coordinator should play a lead role in this process. In the process of verification, the degree of difficulty encountered during the investigation, as well as the degree of cooperation accorded, should be recorded using Annex 4.

The verification process may create difficulties in maintaining the anonymity of those who come forward in the belief they have been discriminated against. In each and every case before verification is undertaken, the process must be explained to the person providing evidence, its implications explored and consent obtained.

❑ **For written texts (laws and internal regulations and procedures)**

For written texts – whether laws or internal regulations and procedures – verification should not pose problems. However, it will be necessary to establish that the written text in question is actually implemented. The accuracy of findings about written texts should be rechecked every time a survey is carried out in order to ascertain any changes in the nature of implementation.

❑ **For practices**

Verification of information regarding practices is much more complicated. Objective verification will not always be possible. Each investigation subgroup should aim to assemble evidence and supporting accounts that may lead to concrete verification.

For this Protocol, it is recommended that at least three independent direct or indirect accounts should be obtained before reaching the conclusion that potential arbitrary discrimination exists in any given area. Cross-references between area representatives and HIV-positive individuals' accounts should be made where possible.

4.7 Determination of arbitrary discrimination

As soon as information has been collected and verified to the best extent possible, each investigation subgroup should prepare for the second meeting. At this meeting, each group should be ready to present well-honed cases with clear supporting documentation that can be examined and classified by the entire investigation team.

The coordinator should take charge of this process. It will involve assessing each situation, weighing and sifting the evidence, and applying the criteria set out in Section 2.2 in order to determine whether there is arbitrary discrimination. De facto circumstances should be taken into account and all the criteria set down in Section 2.2 should be applied.

Once a recorded instance has been classified as arbitrary discrimination, a tick should be placed in the relevant box(es) on Annex 1. Additional situations uncovered during the investigation should not be added to Annex 1, as this would compromise measurement of the Indicator. Such additional situations can be recorded elsewhere.

4.8. Combating arbitrary discrimination

This Protocol is not only intended to be used for the detection of arbitrary discrimination, but also to encourage States and interested organizations, bodies, associations or persons to take measures against such discrimination.

Therefore, investigators should **suggest what change(s) would be likely to help minimize, and ultimately eliminate, the form(s) of arbitrary discrimination they have identified.** They should also **catalogue examples of positive measures for further dissemination.** Annex 5 has been included in this Protocol in order to facilitate these activities.

There is a whole variety of ways of combating arbitrary discrimination, and national AIDS programme managers and other users of this Protocol will need to work together with people living with HIV/AIDS, and their associations, to find and implement imaginative initiatives that take account of local realities.

Measures for combating arbitrary discrimination against persons living with HIV/AIDS include:

- Review and reform of laws. It may be appropriate to consider the drafting of legislative texts to prohibit discrimination based on health status (and not only on the grounds of HIV/AIDS), and also to specify in certain areas those behaviours that are arbitrarily discriminatory.
- Explicit anti-discrimination legislation with criminal and civil sanctions. Criminal sanctions may be appropriate to emphasize the unacceptable nature of certain arbitrarily discriminatory measures.
- Development, dissemination and enforcement of professional codes of ethics/conduct. Interest and initiative in this area should be promoted.
- Information/education campaigns explicitly targeted to promotion of non-discrimination, tolerance, inclusion, and support.
- Development and implementation of workplace policies, including sanctions for arbitrary discrimination. Trade unions and/or staff associations could promote collective agreements in the work setting. Private initiatives should be supported.
- Provision of legal services, and litigation of precedent-setting cases.

4.9. Confidentiality and data protection

The stocking of data on individuals and bodies, even when confidential, entails risks that the steps taken to guarantee confidentiality will not be sufficient and that the persons who have supplied the information – whether as direct witnesses or key informants – will suffer adverse consequences. Information collected during the course of an investigation must be transformed in such a way that follow-up is possible without any of the risks attached to retention of such information, even on a confidential basis.

Investigators must take care to ensure that the information they collect or handle during the course of an investigation is rendered unidentifiable. They must explain the nature of storage and transmission to direct witnesses and key informants, and obtain written consent to such uses.

If any elements of identification do remain, it will be the responsibility of the person in charge of the survey and, ultimately, of those who will analyse the data, to ensure that they are removed.

It will probably be necessary to keep a certain number of accounts and case-studies from one survey to the next in order to determine any changes. **It will therefore be necessary to adapt a rigorous case-by-case approach, keeping information on only those situations that can be followed up without any possibility of actual identification** of the person(s) at the source of the information.

Annex 1. Basic Forms of Arbitrary Discrimination in Key Areas

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
I. Health Care			
1. Refusal to treat on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Different treatment on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Testing without knowledge.			
4. Refusal to inform a person of the result of an HIV test.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Health controls, quarantine, compulsory internment, and/or segregation in hospital, clinic, nursing home etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Compulsory notification of HIV/AIDS status to sexual partner(s) and/or relative(s).			
7. Non-confidentiality: supplying names of individuals found to be HIV-positive to any other party, or knowingly or negligently allowing confidential files to be consulted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
II. Employment			
8. Mandatory testing at recruitment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Mandatory testing during employment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Questions on recruitment forms and/or during interview related to HIV/AIDS status and/or 'lifestyle'.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Lack of confidentiality regarding HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Dismissal, or change(s) in conditions of employment, on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Restrictions due to HIV/AIDS status (e.g. promotion, job location, training and/or employment benefits).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Denial of employment on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
III. Justice/Legal Process			
15. Criminalization of behaviour (such as prostitution or men having sex with men) considered to be conducive to spreading HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Creation of specific criminal offences for deliberate transmission of HIV/AIDS.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Inequality before the law for persons living with HIV/AIDS and in relation to groups regarded as at risk of HIV/AIDS (e.g. refusal to pursue a prosecution where victim is a PLWHA, and denial or limitation of due process protections, including rights of review and appeal, and rights of representation, notice and privacy).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Difference in conviction and/or sentencing on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
IV. Administration			
<p>Prison administration</p> <p>19. Mandatory testing on entry.</p> <p>20. Mandatory testing during prison term.</p> <p>21. Mandatory testing on release.</p> <p>22. Special conditions of detention on grounds of HIV/AIDS status (e.g. segregation, and/or denial of, or reduced access to, prison facilities, privileges and release programmes).</p> <p>23. Restrictions in access to care and treatment.</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
<p>Entry to, and/or stay in, a country</p> <p>24. Mandatory testing, declaration of status, HIV-free certificate required as condition of entry, stay, or freedom of movement.</p> <p>25. Expulsion on grounds of HIV/AIDS status without appropriate procedures.</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p>

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
V. Social Welfare			
26. Denial of, or restrictions on, access to benefits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VI. Housing			
27. Mandatory testing, declaration of status, HIV-free certificate as condition of access to housing or of the right to remain.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VII. Education			
28. Denial of access to education on grounds of HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Restrictions imposed in an educational setting on grounds of HIV/AIDS status (e.g. segregation).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VIII. Reproductive and Family Life			
30. Mandatory premarital testing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Mandatory prenatal testing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Mandatory abortion/sterilization of women with HIV/AIDS.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Withdrawal, or modification, of conditions of exercise of parental custody, support, inheritance rights due to HIV/AIDS status.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Area	Required by law	Required by internal regulations or procedures	Occurring in practice
IX. Insurance and other Financial Services			
<p>34. Denial of, or restrictions on, the granting of social security, or national insurance, on grounds of HIV/AIDS status.</p> <p>35. Denial of, or restrictions on, acceptance for insurance (e.g. life insurance) on grounds of HIV/AIDS status or membership of a group regarded as at risk of HIV.</p> <p>36. Denial of, or restrictions on, access to credit (e.g. bank loan) on grounds of HIV/AIDS status or membership of a group regarded as at risk of HIV.</p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>	<p><input type="checkbox"/></p> <p><input type="checkbox"/></p> <p><input type="checkbox"/></p>
X. Other Public Accommodations and Services			
<p>37. Denial of, or restrictions on, access to other public accommodations or services (e.g. burial services, transport, or sports and leisure facilities) on grounds of HIV/AIDS.</p>	<p><input type="checkbox"/></p>	<p><input type="checkbox"/></p>	<p><input type="checkbox"/></p>

Annex 2. Detailed Description of Instance(s) of Discrimination

Initial survey (insert year)

Step 1

Record

This potentially arbitrary distinction/exclusion/restriction is:

Required by law

Article/Section etc. of Law

The text is:

and/or

Required by internal regulation or procedure

The text is:

and/or

Occurs in practice without a written basis

Step 2

Verified (to the best extent possible)?

Yes

No

Step 3

Is it an example of arbitrary discrimination in accordance with the criteria of Section 2.2 of this Protocol?

Yes

No

Step 4

Can it be recorded on Annex 1 of this Protocol?

Yes

Record it on Annex 1

No

Subsequent survey(s)

Any changes observed since the last survey in respect of this instance of discrimination?

Annex 3. Questionnaires

Remember that all information collected and stored must be rendered unidentifiable.

Questionnaire 1: For Direct Witnesses

Date: _____ Place: _____

Name: _____

Age: _____

Sex: _____

Marital Status: _____

Number of Children: _____

Occupation (present and previous): _____

Is HIV/AIDS status known? _____

Response: spontaneous account
(Use Annex 1 as a checklist of topics.)

The date and place of the instance(s) of discrimination should be specified if possible.

At the end of the interview, ask the person to describe how s/he felt about the treatment s/he has experienced:

Obtain the interviewee's signed consent to the proposed method of storage and transmission of this information.

Signature signifying consent:

Annex 3 (cont.)

Questionnaire 2: For Key Informants

Date:

Place:

Name:

Description of work/activity of key informant (e.g. association providing free legal advice to persons living with HIV/AIDS):

Is the study of arbitrary discrimination part of the key informant's activities?

Number of persons living with HIV/AIDS encountered by key informant:

Response

(Include account of instances of potential arbitrary discrimination encountered. Use Annex 1 as a checklist of topics.)

The date and place of the instance(s) of discrimination should be specified if possible.

Obtain the interviewee's signed consent to the proposed method of storage and transmission of this information.

Signature signifying consent:

Annex 4. Record of Degree of Difficulty/Cooperation Encountered

For each of the following sectors/organizations, rate: (1) the degree of difficulty encountered in obtaining access to internal regulations and procedures; and (2) the degree of cooperation accorded.

Areas	1. Level of Difficulty Encountered		
	Low	Medium	High
Public bodies, organizations or groups (list and rate each one approached)			
Private bodies, organizations or groups (list and rate each one approached)			
	2. Degree of Cooperation Accorded		
	Low	Medium	High
Public bodies, organizations or groups (list and rate each one approached)			
Private bodies, organizations or groups (list and rate each one approached)			

Annex 5. Combating Arbitrary Discrimination Checklist

Initial survey

General

1. Is the State centralized or federal?
2. How is the division of responsibilities organized in the various areas studied under this Protocol (e.g. ministries; federated entities; provinces; communities)?
3. What are the sources of law (e.g. a written constitution; legislation; judge-made law; custom)?
4. Is the State a party to any regional and/or international human rights instruments?

Means/structures that could be used to help combat arbitrary discrimination

1. Is the State a party to the International Covenant on Civil and Political Rights?
 - If so, what provisions are there for its application within the country? Can it be directly invoked in the courts?
 - Has the State ratified the Optional Protocol concerning the Human Rights Committee?
 - Has the State made any reservations to the Covenant and the Optional Protocol?
2. If the State is a party to other international or regional human rights instruments, do any of these provide a possible means of recourse against arbitrary discrimination?
3. If the State has a written constitution, does it provide a possible means of recourse against arbitrary discrimination?
4. Is there any anti-discrimination legislation? Can it be applied to persons living with HIV/AIDS?
5. Are there internal regulations or procedures that prohibit discrimination? If so, give as complete a description as possible.
6. Are there practices or agreements (of the convention or collective bargain type) that prohibit discrimination? If so, give as complete a description as possible.
7. Have any committees, groups, non-profit associations, NGOs, etc. been set up and authorized to monitor the implementation of the principle of non-discrimination? If so, give as complete a description as possible.

8. Are there any committees, groups, non-profit associations, NGOs, etc. whose social objectives are to aid, support or defend persons living with HIV/AIDS? If so, give as complete a description as possible.
9. Do these agencies have the right to appeal before the courts? If so, do they have the right to appeal against violations of the rights of their members?
10. Have there been any information campaigns or educational activities specifically to combat arbitrary discrimination against persons living with HIV/AIDS within the last two years? If so, give as complete a description as possible.

Subsequent survey(s)

Modifications and/or abolition of arbitrarily discriminatory law, regulations and procedures, and practices

1. Which, if any, of the forms of arbitrary discrimination that existed in regard to persons living with HIV/AIDS have been modified or abolished? Where modification or abolition has occurred, explain how this happened.
2. If there has been no modification and/or abolition of arbitrarily discriminatory measures since the initial survey, list the possible reasons for this.
3. Have rulings relating to discrimination been obtained in jurisprudence?
4. If not, list the possible reasons.

Annex 6. Orientation Programme for Investigators

Training Course Agenda (1 Day)

Introduction

8.15-8.30 *Domestic arrangements (e.g. payment; travel; and subsistence)*

8.30-9.00 **Aims of the Protocol and this particular investigation**

9.00-9.30 **The particular features of HIV/AIDS and how these affect individuals and society**

Consider dividing investigators into two groups, with a lawyer, social worker and NGO representative in each.

Issues to discuss include latency; no vaccine; modes of transmission; and public health concerns.

9.30-10.30 **Non-discrimination and human rights: Basic concepts**

Issues to discuss include stigma (felt and enacted) and forms and sources of discrimination; the centrality of non-discrimination within human rights and its role in securing public health goals; reference to particular regional and international human rights instruments, in particular those to which the State is a party; reference to domestic legal provisions on non-discrimination (e.g. written constitution, anti-discrimination legislation); and the definition of arbitrary discrimination.

10.30-11.00 *Break*

11.30-12.30 **General discussion of Protocol methodology and data collection**

Issues to discuss include the Protocol's identification of 37 situations in 10 key areas; its focus on three sources of potential arbitrary discrimination; using the Annexes; and the Indicator equation.

There should also be discussion of how the different areas will be divided up between the investigators; the problems posed by the different areas and sources of potential arbitrary discrimination; and how direct witnesses and key informants can be targeted.

12.30-13.30 *Lunch*

13.30-14.00 **Role-play problems in data collection**

(Materials required: overhead transparencies and projector; coloured cards for problems/solutions.)

Use small groups of two or three. Each group should consider data collection problems specific to their particular area(s).
Alternatives and solutions should be actively sought.

14.00-14.30 **Feedback and discussion on role-play problems**

(Materials required: overhead transparencies and projector.)

Feedback from groups and discussion involving critical appraisal on each area.

The Programme Facilitator can use the role-play scenarios (see below) to get the investigators to examine the question of arbitrary discrimination. By involving the whole group, a consistency of approach in gathering evidence and making judgements about the existence of arbitrary discrimination can be facilitated.

14.30-15.00 **Specific issues in methodology I: Confidentiality and data protection**

Issues to discuss include handling, storage and transmission of data; processes for rendering information unidentifiable; confidentiality and data protection challenges presented by direct witnesses and key informants; and obtaining written consent.

15.00-15.30 *Break*

15.30-16.30 **Specific issues in methodology II: Measurement of the Indicator – usefulness and limitations of the Protocol**

Issues to discuss include problems of access and verification, and bias.

16.30-17.00 **Specific issues in methodology III: Principal areas under investigation**

Health Care; Employment; Justice / Legal Process; Administration; Social Welfare; Housing; Education; Reproductive and Family Life; Insurance and other Financial Services; and other Public Accommodations and Services.

Issues to discuss include whether these principal areas are appropriate; whether there are any significant missing area(s); is it easy to access information; and from where/whom can data be collected?

17.00-17.30 **Small groups to consider Protocol methodology in particular areas**

Issues to discuss include dealing with the three different sources of potential arbitrary discrimination (i.e. law, internal regulations and procedures, and practices

without a written basis); obtaining and conducting interviews with direct witnesses and key informants in the different areas.

17.30-18.00 **Feedback on investigation methodology: Small groups**

Each group should provide feedback on its conclusions and solutions for critical appraisal by others.

18.00-18.30 **Timetable for data collection, visits, review and analysis**

Issues to decide include data collection phase (two weeks); first review meeting; analysis and second meeting; and report writing.

18.30-19.00 *Break and general discussion*

19.00 *Close and dinner*

Role-play exercises for investigators in orientation training

Role-play of interviews is useful for several reasons. It helps investigators to practise interviews with different types of respondents. It also helps them to understand the aims and objectives of the Protocol, as well as its processes and methodology (including the definition of arbitrary discrimination). Role-plays are particularly useful where investigators do not do this kind of work in their daily lives: they help to emphasize the importance of full examination of evidence and uncovering as many of the facts as possible during an interview.

Role-play helps investigators:

- practise interviews they will carry out with key informants;
- practise interviews they will carry out with persons living with HIV/AIDS;
- understand the aims and objectives of the Protocol;
- understand the definition of arbitrary discrimination.

Investigators should divide into groups of two or three for the role-plays. Within each group, individual investigators should be asked to undertake in turn the role of the investigator or respondent in: (a) interviewing a person living with HIV/AIDS; and (b) interviewing a key informant about possible examples of discrimination in his/her organization, company, association, etc. Participants should be asked to be as creative as possible when playing the role of the respondent.

A range of role-plays can be used. The Programme Facilitator may choose to draw on examples from the particular country under study. The following are two examples from field-tests on this Protocol:

Role-play 1

An HIV-positive individual, A, was tested while working abroad and was subsequently expelled. On returning to her country, she was rejected by her family and later became ill. On entry to the local hospital, the staff suspected HIV infection and isolated A in a separate ward. The doctors refused to treat her and she was transferred without being told why to a hospital specializing in AIDS.

In this scenario, *only* the hospital treatment can be the focus of the investigation. While the foreign country has obviously behaved in a discriminatory fashion, this is not the focus of the present investigation. This investigation is only concerned with arbitrary discrimination on the grounds of HIV/AIDS within the home country. Similarly, although the reaction of A's family is obviously very distressing for A, it does not fall within the definition of institutional discrimination for the purposes of this investigation.

Role-play 2

An HIV-positive patient, B, has been without employment for some time. Previously, she worked as a machinist at a clothes factory. B had an accident at this workplace and lost an arm. Her injury necessitated a blood transfusion. As a result of this transfusion, B became HIV-positive. The company refused to re-employ her and denied her compensation.

In this scenario, the compensation for HIV infection is owed by the hospital not the company. The company may owe B compensation for an accident at work.

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.



Joint United Nations Programme on HIV/AIDS

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Joint United Nations Programme on HIV/AIDS (UNAIDS)

20 avenue Appia, 1211 Geneva 27, Switzerland

Tel. (+4122) 791 46 51 – Fax (+4122) 791 41 65

e-mail: unaids@unaids.org – Internet: <http://www.unaids.org>