In Focus

HIV—to test or not to test?

World AIDS Day has been established as an annual event to be marked on 1 December each year. The first was held in 1988, when worldwide activities were coordinated by the World Health Organization (see Vol. 10, No. 1, page 136). As part of the 24-hour event held in Geneva, a debate took place on the ethical aspects of AIDS. We publish below an edited version of part of the discussions; the views expressed do not necessarily reflect the policy of WHO. The Editor of World Health Forum would be pleased to hear from readers who have practical experience of ethical problems relating to AIDS and HIV infection, and the steps taken to overcome them.

Dr Sartorius: AIDS raises an array of ethical issues relevant to our life, our society, our survival and the very survival of the human race. Many of them are directly concerned with the treatment of disease, the funding of research, the organization of health services, and the structure of society itself. Almost any measure proposed to deal with AIDS and HIV infection raises issues related to the rights and duties of individuals and to the balance between them and the rights and duties of society. Perhaps in attempting to resolve some of these issues in regard to AIDS we shall learn how to deal with diseases that may come tomorrow, and might even be more lethal and terrible than AIDS. If so, our discussion here of ethical issues may have even wider application than to AIDS-related problems alone.

Dr Dawson, would you like to start the discussion by telling us what is being done in the United Kingdom with regard to testing and screening?

Dr Dawson: First of all I should like to differentiate between “testing” and “screening”. I use the term “testing” to describe a test for HIV antibodies or for the virus itself done on an individual to produce an identifiable result, which is linked to that...
person and may be either voluntary or involuntary. I use the term “screening” to talk about testing samples of blood to provide information about the spread of HIV within a population.

In the United Kingdom we have just approved anonymous prevalence screening. This will mean doing more than 100,000 tests each year for the foreseeable future on samples of blood. There will be no question of obtaining individual consent but, because the blood is anonymous at the time of the laboratory examination, there is no possibility of linking the result to an individual person and thus no possibility of harm. The benefit to society is that it will give us—by age, sex and geographical region—information about how HIV is spreading within our community.

The screening programme is totally separate from the provision of tests for individuals who are worried, or whose doctors are worried on their behalf, that they may be HIV positive and where the result must be established and linked to the individual. It is clear that such tests should be done only with specific consent of the individual: there is the possibility of great social or financial harm and he or she must appreciate what is involved in order to give consent.

I hope it is helpful to separate the two activities: in the case of anonymous screening, where there is no possibility of harm to the individual but the certitude of great gain to the community, we believe we can do the tests without consent; on the other hand, where results are identifiable the test should be done only with the specific consent of the individual.

Mr Justice Kirby: I think no one could have any moral or ethical qualms about anonymous testing of samples of blood. But that’s not what the community means when talking about “mandatory testing”. What is meant is either mandatory testing of the whole of the population or of particular groups. In many countries the latter has already been implemented, but I am not sure that any country has yet implemented the former.

I think it is very important to keep in mind the economics of morality—that is to say, not only the moral quality of decisions but also that decisions cost money to implement. The recent United States law on mandatory testing of particular groups (for example, applicants for marriage licences) has now come into force in a number of States. A review showed that it cost US$ 228,000 to detect an HIV-positive applicant; it also revealed that in the State in question applications for marriage licences fell by 25%. So when we consider the laws or policies that are introduced to provide for mandatory testing of, say, prisoners (who are a vulnerable group), we have got to ask, what are we going to do with the figures when we get them? When we think about mandatory testing of marriage licence applicants, we have to ask ourselves, is this going to be effective? What are we going to do about the very small number of positive applicants that we find? And—above all—is it money well spent or would that money be better spent on education? Are we going to prevent HIV-positive applicants from getting married or are we simply going to require that each such partner give informed consent?

As to testing the whole population, we have to keep in mind the enormous cost of such a measure and also the fact that the results would never be entirely accurate. The test for the antibodies would not detect the virus; moreover, a person might “pass” one day and “fail” the next. So it’s not a very effective way to spend the health dollar. I
think the message that should go round the world from this World AIDS Day is that the cheapest, most effective control of AIDS is through public education. Most citizens have tuberculosis and other infectious diseases in mind when they think that mandatory testing of the whole population is the way ahead. The experts have to tell the world that AIDS is different: mandatory testing would be ineffective, inordinately expensive, and carry in its train very great risks of discrimination.

Professor Pokrovski: In the Soviet Union we have a policy under which voluntary and involuntary forms of testing co-exist. There are certain groups of the population who, under the law, are tested compulsorily, such as prisoners and prostitutes. At the same time, there is a service to which people who suspect that they may be infected can go, provide their blood, and receive the result, all anonymously. Here I should like to draw your attention to one further point: there should be maximum trust between the patient and medical workers so that the anonymous infected people very quickly become aware of their infection and can be helped by their doctors. Then, through confidential conversations with them and their acquaintances, we discover an epidemiological link in the chain of infected people. I would say that almost half of the hundred-odd people who are now listed as carriers were detected thanks to this trust and confidence.

It is entirely a different story when we have an abnormal unhealthy attitude to an infected person. This is something to be avoided. For example, in Leningrad, a lady died and there was a posthumous diagnosis of AIDS. The local authorities publicized the affair and appealed to anyone who may have had sexual contact with her to come forward. Not surprisingly, not a single person came for testing. No doubt this incident undermined the confidence in the chain between patients and medical services and the ethical confidence that must be maintained. Our goal must be complete mutual understanding and confidence, in which the most important factor is individual work and contact with people.

I should like to ask Dr Dawson how he intends organizing the collection of blood from the 100,000 people a year that he mentioned. In principle, I personally think that total screening of the population for AIDS is senselessly throwing away money and may involve moral harm, making it counterproductive.

Dr Dawson: Initially, testing will be done on samples of blood which are taken in any case, so no special collection of blood is involved. I believe the group that will provide the most useful results will be antenatal patients; pregnant women can be tested in the course of one of their routine visits to an antenatal clinic, and also newborn babies whose blood is tested anyway for other reasons. We are talking about blood which is taken anyway, a sample of which can be passed anonymously—and I stress this—to a central laboratory separate from the hospital where the woman has been seen, so anonymity can be guaranteed. This is also important for quality control: the very low rate of positive results that we would expect in this group makes it important for the test to be done in one laboratory where there is one standard of quality control, otherwise we might well find that the incidence of false positives—and perhaps false negatives—would destroy the value of the figures.

Dr Kouchner: I should like to thank Dr Dawson for his explanations and to support the views of Mr Kirby. I should also like to focus on two problems which are receiving the public's attention. First, there
is resistance in a number of countries, including my own, to systematic screening; there is the feeling that “compulsory” is a very important word in all this. Screening has been discussed for three situations in life: before marriage, during pregnancy, and before surgical operations. I have the impression that the public feels—and perhaps the very important role of the press needs to be stressed here—that there is resistance on the part of the medical profession or the government to protect the general public by undertaking systematic screening of all potential patients. Here I think Mr Kirby’s detailed analysis of the economics involved is very useful, and we also need specific explanations in moral terms.

Second, I think we need to stress in particular the delicate task of announcing seropositivity to the patient. I have been working with a number of nongovernmental organizations in France where tests are done free and I shall never forget the first patients to whom we had to announce that they were seropositive. Psychological and medical counselling are essential before, during, and especially after informing the patient. We cannot simply test people and then leave them to their own devices. Follow-up is of paramount importance, in order to resolve all the questions that arise from seropositivity.

**Miss Bailey:** I think the primary concept that really stands out is trust. I entirely agree that one has to have absolute trust in the physician once the word AIDS is pronounced. But trust should not be limited to the patient/physician relationship, it has to be general too. In the entertainment profession it is strange the way a rumour starts: first of all it’s highly confidential, and the next thing you know it’s an open secret. Rumours are the most insidious things in the world, and the more they spread the more the person concerned wants to hide away even if the rumours are unfounded. It has come to the point where some people don’t even want to shake hands with others because they heard a whisper. Find the way to foster trust and you will have found how to get people to open up and say, “I have AIDS”.

**Professor Dembelé:** The very fact that we are discussing the problems of individuals vis-à-vis society means that there is a problem. In fact, it is a very simple one. AIDS has given rise to so many fantasies in people’s minds that in almost all countries there are pressures from certain people who demand that we take special measures to protect those who are not infected with HIV from those who are. Unfortunately, some authorities have yielded to such pressures and some countries are preparing to introduce systematic testing on entry. We know very well that in public health this type of measure is completely futile. So the medical profession has a very important duty to explain things clearly and the mass media must take responsibility for putting the messages across in a very clear manner. A bridge has to be built between all parts of society.

**Dr Castro:** On the ethics of screening, I am concerned about protecting individuals and avoiding prejudice against certain sectors of society or certain racial groups on the pretext that we are scientifically combating a disease. We need to be very careful when we get into the area of compulsory testing; such a step could be manipulated into discrimination on ethnic or other grounds. It may be in contradiction with what I am saying, but I wonder whether testing would be necessary for those who enjoy a high economic level in a developed culture and who go to establish themselves in other countries where there is not the same educational level or the economic and
cultural means of defence. I am thinking, for example, of overseas military bases of powerful countries; perhaps in these circumstances there is an even greater moral responsibility incumbent upon those who enjoy all the advantages—including military—to protect their population and the populations into which they move.

To sum up my views, I agree that protection and support of individuals, which have already been stressed here, are absolutely essential and that the protection of groups at risk of racial and other discrimination should be ensured.

**Dr Sartorius:** Mr Keilau is working here in Geneva at the Centre for Human Rights. I think it is appropriate that he tells us how this looks from the point of view of human rights. Does mandatory testing constitute an infringement?

**Mr Keilau:** I think that any testing or medical check-up, whether mandatory or voluntary, does not affect human rights because, generally speaking, any medical treatment is a kind of testing. If you were to say that medical treatment affected human rights then we should not have any medical services at all. The important ethical point seems to me to be, what will be done with the results obtained? How will people with a positive result be treated? If you consider the present situation, there are now two kinds of persons. We have persons infected with HIV or suffering from AIDS, and we have non-infected or non-yet-infected persons. All of them are human beings, so all of them have the same human rights. We should be extremely careful not to establish a new minority by singling out persons infected by HIV or suffering from AIDS. We have to protect the dignity, the human rights, and the human behaviour of all of them. This is how I see the essence of the subject. In looking into the necessity or otherwise for obligatory testing, we have thus to take into account the ethical fact of preserving the dignity of persons, not to discriminate against them if the results are positive: not to separate them or stigmatize them in any way.

**Dr Dawson:** I want to re-emphasize the importance of good science in tackling this disease. If we abandon science and the careful, logical analysis of information, then we shall greatly disadvantage ourselves in the fight against AIDS. For that reason I support the prevalence screening which will give us information about the pattern of the spread of HIV within the population. However, that must be kept quite separate from any question of mandatory testing. I share the views expressed here that mandatory testing would be grossly prejudicial to human rights, but—and this is perhaps even more important—it would be ineffective and would give us a false sense of complacency; it would therefore not contribute to limiting the spread of HIV infection.

**Rabbi Garai:** It seems to me that there are other questions underlying this particular issue. According to the specialists it appears that mandatory testing serves no useful purpose, so in principle moral problems should not arise. But when we talk about screening or testing we must weigh human rights against human responsibilities. A group, in principle, has the right to know what is happening within it; but this right carries an accompanying responsibility towards each individual within the group. In the same way, an individual must reflect on his own responsibility towards others who have the same rights as he does, co-existing the one with the other. It is difficult to legislate in general terms because each case involves a specific individual human being. Because of this, no generalization is possible, as categorization of individuals is
undesirable. Each case must be considered on its own merits with full respect for rights and full awareness of responsibilities.

Father Professor Carrasco: From what I have heard so far, I think the most important idea that has been expressed is the problem that arises once a person has been identified as having AIDS. As I see it, in our general consideration of the detection of patients, this is the question to which we should address our attention above all. Once we have detected a certain percentage of the population or certain individuals as having AIDS, are we going to prohibit them from getting married if they freely wish to do so and have exchanged sufficient information with their partner? Are we going to prevent them from having children? Are we going to tell them, “You have an incurable disease and we only have palliative remedies available to us”? These are the questions, and perhaps others, which many of you will have in mind, and they are the ones that I think we should be considering when we discuss the diagnosis or detection of AIDS sufferers.

Dr Sartorius: It is important to recognize that as we are talking about screening and testing, different criteria are being invoked. We are speaking about human rights, but also about the legal and economic issues, about effectiveness and about practical consequences for the organization of health care. I think that depending on these different points of view and their interaction the same questions might receive slightly different answers. It is very likely, for example, that a significant increase of efficiency of a screening method or a significant decrease of its price may lead us to a different position concerning screening in a few years’ time. In planning services one has also to think about the pragmatic aspects such as: will the measure which we are proposing give us useful information? Will it decrease the probability that people will come forward? Will it decrease our opportunities to educate and to work with people? We shall probably find that each of these practical aspects needs consideration from three angles: does it work? is it legal? and, is it moral? It will be by somehow combining answers to these three questions that we shall arrive at a consensus, which, however, will last only until we obtain new data: no consensus will last us for ever.

Mr Justice Kirby: Obviously if a proposed line of action doesn’t work, then there is no point in pursuing it. The second question is, is it legal? Well, every state can make it legal or illegal according to its own legal system, so I don’t really think that creates much of a problem. However, it is relevant to the first question because there is tremendous pressure upon politicians to do something. This pressure will be growing. I am afraid that people who find themselves in this predicament would be impatient with the debate which we have just had. That is why the first question is so important. As Dr Dawson says, we must base our policies on good data: good ethics will grow out of good data. If we know that it is grossly cost-ineffective to test the whole population, then it is pointless for us to pursue that solution. And yet probably the majority of people would think that is just what we should do, remembering the old diseases like tuberculosis.

We who know a little more about HIV and AIDS have to try to explain to public leaders and to our communities that mandatory testing of the whole population is an exorbitantly expensive and generally ineffective response to this pandemic. There are going to be tremendous demands on our resources because of HIV and AIDS. So we
have to spend our money more effectively. Mandatory testing also carries the risk of very great discrimination.

I must say that I was very impressed to hear that condoms are made available to prisoners in Switzerland. They won’t do that in most parts of Australia: instead there is mandatory testing of prisoners. But what use is this? We then know who is infected in the prison population. So testing may have some marginal epidemiological value. But simply to take that data and not to provide prisoners with the means of stopping the spread of the virus in prisons seems to me to be very serious hypocrisy on the part of the authorities. Sadly, there is going to be a great deal of hypocrisy before this epidemic has run its course. I would suggest that a lot of countries, including my own, can learn from what is being done elsewhere. We should all be ready to copy useful initiatives.

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**AIDS—no country can fight alone**

The global fight against AIDS will take many years and it will require political and health leaders alike to have the strength of commitment necessary to make difficult decisions, to stand firm against unreasonable fear and to maintain the consistency and unity of action that are absolutely vital for a global fight against this global threat.

No country can fight AIDS on its own. The leadership necessary to coordinate our efforts can come only from the World Health Organization. WHO is the linchpin holding together our individual efforts and guiding them into a genuinely unified global attack on AIDS.