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THE RIGHT TO UNRESTRICTED ACCESS TO VOLUNTARY AND CONFIDENTIAL OR ANONYMOUS HIV TESTING: INTERNATIONAL LAW ASPECTS

The article offers a general analysis of the protection of the right to unrestricted access to voluntary, confidential or anonymous HIV testing by international law. It is noted that unrestricted access to HIV testing is an element of the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The article describes the formal requirements for the protection of the right to unrestricted access to voluntary, confidential or anonymous HIV testing. It highlights that HIV testing should be accompanied by quality pre-test and post-test counselling and related services. It is noted that arbitrary, mandatory or compulsory HIV testing is prohibited. Nevertheless, arbitrary, mandatory or compulsory HIV testing continues to occur in many countries and that is why there is a need for further improvement of national legislations in this area.

Key words: rights of people living with HIV/AIDS, HIV testing, voluntary consent, the right to the highest attainable standard of health.

A large number of people living with HIV/AIDS (further – PLWHA) are unaware of their serological status (presence or absence of antibodies in serum). Recent studies show that about one-third of HIV-positive people in the EU are unaware of their status, while in some countries in Eastern Europe and Central Asia more than 60% of PLWHA remain without a definitive diagnosis [1]. However, **everyone has the right to unrestricted access to voluntary, confidential or anonymous HIV testing with high-quality pre-test and post-test counselling and related services.**

The main purpose of the article is to analyse the features of ensuring the right to unrestricted access to voluntary, confidential or anonymous HIV testing through international human rights law.

Studies of domestic and foreign scholars and practitioners tend to focus on the prevention of HIV/AIDS. The rights of people living with HIV/AIDS are at best of secondary importance. Issues concerning certain aspects of the right of everyone to unrestricted access to voluntary, confidential or anonymous HIV

testing are highlighted in the works of R. Jurgens, D. Tarantola, S. Graskin, R. Elliott, R. Rajkumar, R. Brookmeyer etc.

According to Art. 12 of the International Covenant on Economic, Social and Cultural Rights (1966), «the States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health». The steps to be taken by states to ensure this right shall include «the prevention, treatment and control of epidemic, endemic, occupational and other diseases» and «the creation of conditions which would assure to all medical service and medical attention in the event of sickness» [2].

Some international human rights treaties also emphasized the importance of the principle of non-discrimination in the promotion and protection of the right to health. Thus, in accordance with Art. 12 of the Convention on the Elimination of All Forms of Discrimination against Women (1979), states «shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services (...)» [3]. A similar provision is enshrined in Art. 5 (e) (iv) of the International Convention on the Elimination of All Forms of Racial Discrimination (1965) [4].

It is important to note that the lack of resources does not exempt the states from the obligation to take steps in order to ensure the right to the highest attainable standard of health [5]. Thus, in accordance with para. 43 of the General Comment №14, states have the primary obligation to ensure at least *a minimum essential level of the right to health*, the main components of the core content of which *inter alia* are:

- 1) ensuring equal access to all health facilities, goods and services, especially for vulnerable or marginalized groups;
- 2) ensuring equitable distribution of *all* health facilities, goods and services;
- 3) developing of a national public health strategy and an action plan that address the health care needs of the entire population based on epidemiological data and their implementing [6].

It is worth mentioning, HIV testing and counselling are important not only for individuals but for society as a whole, as they are aimed at reducing risky behaviour. In addition, HIV testing and counselling enable PLWHA to protect others against HIV and to get access to HIV treatment and care in the early stages, thereby reducing risk of getting or transmitting HIV and mortality rate.

HIV testing must be conducted in accordance with international human rights standards and be combined with effective interventions aimed to reduce stigma, discrimination and to protect the confidentiality of HIV test results. In addition, it must always be accompanied by related services (e.g. consulting on a variety of HIV/AIDS-related issues). At the same time, strict observance of confidentiality is of paramount importance because it is almost the only incentive to individual to be tested and in the case of HIV-positive status to use health services [7, p. 52].

Before the advent of antiretroviral therapy, HIV testing not only on the initiative of individuals, but also on the initiative of medical institutions on condition of voluntary consent was considered quite acceptable. It could be explained that despite the fact PLWHA face significant stigma and

discrimination, identifying people living with HIV/AIDS was an important task to meet the needs of population-based public health. This approach has caused objections because simply increasing the number of people being tested for HIV is not an adequate purpose if the impacts of HIV testing are not taken into account. Therefore, states should not expand HIV testing programs but create favourable conditions under which a person wants to know the serological status and trusts medical institutions that conduct HIV testing, which is important for providing the both parties with all the necessary information [8, p. 323].

WHO and UNAIDS support scaling up of HIV testing and counselling on the initiative of individuals, but also recognize the need for testing on the initiative of medical institutions because they are in direct communication with persons who possibly will need essential HIV and AIDS-related services [9].

They recommend this model in conjunction with providing the basic information every time a person independently requests a HIV test. In addition, post-test counselling regardless of the result (positive, negative, or indeterminate) of HIV test should be conducted. Based on this approach, it is recommended to conduct HIV testing:

- 1) of all patients whose symptoms can be caused by HIV;
- 2) as part of routine medical care in generalized epidemic* (e.g. in the context of prenatal care and sexually transmitted diseases (STDs) treatment);
- 3) more selectively when the epidemic is still considered low or concentrated** or in its early stages***, when HIV testing is initiated by the healthcare facilities, also epidemiological and social factors should be taken into account [7, p. 52].

WHO and UNAIDS emphasize that concerns about coerced HIV testing can be avoided through proper training and supervising health care workers and institutions and providing a thorough monitoring of HIV testing programs that they offer. Health care workers should provide their patients at least the minimum information to receive their consent to perform HIV testing [9; 11]. For example, information about the reasons for testing, the clinical benefits and risks of testing (stigmatization, discrimination etc.), about the services available in case of negative or positive results of HIV test (including the availability of antiretroviral therapy) and the guaranteed confidentiality of HIV test results.

* This means that HIV is firmly entrenched in «key» populations. Despite the fact that vulnerable groups may still accelerate the spread of HIV, sexual relations among people may be sufficient for the further spread of the epidemic independently of these groups. In addition, the prevalence rate of HIV among pregnant women consistently exceeds 1%.

** HIV is spreading rapidly among groups of individuals whose behaviours increase HIV risk (homosexuals, transgender people, prisoners, sex workers, drug users, etc.), while not being widespread among the general population. Further development of the epidemic depends on the frequency and nature of the relationships between these and other groups. HIV prevalence consistently exceeds 5% at least in one of the groups. Among pregnant women in urban areas, HIV prevalence is below 1%.

*** HIV prevalence has not reached a significant level (less than 5%) among any of the groups. Registered cases of HIV infection are usually related to people whose behaviours increase HIV risk.

Arbitrary, mandatory or compulsory forms of testing violate ethical norms and the individual's right to consent or dissent to medical intervention, rights to privacy and personal security. According to the International Guidelines on HIV/AIDS and Human Rights (consolidated version, 2006). HIV testing should be conducted implicating the human rights-based approaches and with the understanding that the interests of public health do not justify mandatory HIV testing, except in some cases (for example, testing donors of blood, organs, tissues, cells or biological fluids, when human biological materials are tested and not the person [12].

As a rule, most states have enacted laws that provide for mandatory HIV testing only for certain categories of persons and in certain situations. Another example of violation of the principle of voluntariness is a situation when HIV testing according to the laws of this or that state is officially voluntary, but people may be coerced in more or less hidden form into HIV testing. Most tests are conducted without the consent of the patient and the purpose of those tests is not to provide access to prevention, treatment, care and support for people living with HIV/AIDS but to limit the access of HIV-positive people to different services or to apply any other restrictions to them.

Therefore, HIV testing should be voluntary and accompanied by informed consent, counselling and confidentiality [11]. It is about the standard of HIV testing or rather three principles – the so-called «three C»:

- 1) **counselling** and informing about HIV/AIDS before and after HIV testing;
- 2) concretely expressed, informed and voluntary **consent** of the patient for testing;
- 3) **confidentiality** of HIV test results and the fact of requesting a HIV test.

The requirement of informed consent is enshrined in a number of international legal acts on the rights of patients. Thus, in the Nuremberg Code (1947) it is indicated, that voluntary consent is *under any circumstances* a prerequisite for any medical intervention, involving human subjects. Furthermore, according to para. 22 of the World Medical Association Declaration of Helsinki «Ethical Principles for Medical Research Involving Human Subjects» (1964), the physician should «obtain the subject's freely-given informed consent, *preferably in writing*. If the consent cannot be obtained in writing, the non-written consent must be *formally documented and witnessed*». According to the Art. 3 of the Declaration on the Promotion of Patients' Rights in Europe (1994), a patient «has the right to refuse or to halt a medical intervention» at any time.

The right to informed consent is enshrined in some regional human rights treaties too. According to Art. 5 the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (1997), any intervention in the health field may be carried out only after the voluntary and informed consent of the person on it. Additional Protocol to the Convention on Human Rights and Biomedicine concerning the Biomedical Research (2005) complements the provisions of this Article.

Thus, an informed consent is an integral part of the right to the highest attainable standard of health; a requirement, that protects the right of patients to participate in medical decision-making and establishes legal and ethical

responsibilities of health care workers. It is not just about the person's consent to medical intervention but the **informed** (taken by the person after being familiarized with all the specificities and characteristics of medical research that may affect him/her) and **voluntary** (without coercion, undue influence or misrepresentation) decision [13]. Informed consent should be obtained from the patients in accordance with the procedure provided for by law [14]. At the same time, privacy requirements must to be followed. Thus, informed consent should be obtained only in a private setting, and post-test counselling or any other forms of interaction with HIV-positive patients should be held separately from other patients or medical staff. The right to accept medical intervention, refuse it or choose an alternative medical intervention is based on the patient's competence. As a rule, any problems related to giving consent by a person who has reached the age of majority do not occur. Regarding the problem of obtaining consent for HIV testing for children, according to the recommendations of the WHO and UNICEF, states should:

- 1) develop a policy that clearly specifies who can give consent for the child and at what age children can give such consent on their own behalves;
- 2) amend the relevant legislation in order to increase the number of people with free access to HIV testing by lowering the age at which children can give their consent (e.g., from 18 to 14 or 12 years), that will allow «mature» or «emancipated» minors to take such decisions on their own behalves or, alternatively, empower persons which take care of children or heads of medical institutions to provide the right to consent for the child if any parent or legal guardian do not have the opportunity to give it;
- 3) develop a policy responding to parental refusals of HIV testing of children, if the test is to be carried out with regard to clinical indications and in the interests of the child, etc.

In order to ensure informed consent, each patient should have *an equal access to timely, effective and accurate public health information and data*, including information about HIV/AIDS, which is understandable (health workers should provide information to the patient in a language that is comprehensible, taking into account patient's level of knowledge, intellectual skills and literacy level; they must also make sure that this information is not too technical, complex or hasty [14]) and takes into account different cultural, religious and ethical factors.

Because HIV testing cannot be arbitrary, mandatory or compulsory, testing for such purposes as obtaining travel documents (like visas), reception of documents and enrolment for studies, employment and periodic medical examinations of some categories of workers (e.g. military, health care workers etc.) violates fundamental human rights. The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health criticizes mandatory and periodic HIV testing as it limits and threatens human rights and at the same does not justify the aim to meet the needs of population-based public health. Compulsory HIV testing can:

- 1) result in inappropriate providing information and counselling;
- 2) keep people from accessing HIV test results and related health care services;

- 3) result in imprisonment of PLWHA and violation of the right to personal integrity;
- 4) lead to increasing of HIV-related stigma and discrimination (especially this issue is actual for those categories of persons, which because of structural inequalities cannot protect themselves effectively as they fall within the ambit of government institutions or the criminal law (such as soldiers, prisoners, injecting drug users, men who have sex with men, refugees, etc.)) [14].

The right to unrestricted access to voluntary, confidential or anonymous HIV testing with quality pre-test and post-test counselling and related services is based on such guaranteed by international law human rights and fundamental freedoms, as: the right to health, which includes the right to control one's health and body, the right to liberty and security of person, the right to privacy and the right to freedom from scientific experimentation, including medical, without free and informed consent derived from the protection of all persons from being subjected to torture and other cruel, inhuman or degrading treatment or punishment (Art. 7 of the International Covenant on Civil and Political Rights (1966), Art. 12 of the International Covenant on Economic, Social and Cultural Rights (1966), General Comment № 14, etc.).

Thus, in 2009 the Supreme Court of Zambia emphasized that the decision of the Zambian Air Force about HIV testing their employees Stanley Kingaipe and Charles Chookole without consent violated the right to privacy and freedom from torture or cruel, inhuman or degrading treatment or punishment enshrined in the Constitution of Zambia. In addition, in its decision the Court refers to the obligations of Zambia under international and regional treaties on the protection of human rights and fundamental freedoms [15]. It is worth mentioning the case *Jimson v Botswana Building Society* [16] concerning compulsory testing for HIV of Rapula Jimson, an office worker in Botswana Building Society, during his trial period. In its judgment, the Industrial Court addressed to the Parliament of Botswana demanding to resolve the issue of mandatory HIV testing, which violated human rights and freedoms.

As can be seen, HIV/AIDS raises many public health issues. These issues are usually related to unlawfully limited basic health care services, particularly voluntary, confidential or anonymous HIV testing. Arbitrary, mandatory or compulsory HIV testing continues to occur in many countries. That is why there is a need for countries to review their laws and practices requiring or permitting such testing to explicitly prohibit it.

In summary, we can conclude that an international standard for the protection of people living with HIV/AIDS rights based on the existing rules of international human rights law and practices of international organizations and bodies is formed. According to this standard, the states should ensure the right to unrestricted access to voluntary, confidential or anonymous HIV testing with high-quality pre-test and post-test counselling and related services in practice and prohibit arbitrary, mandatory or compulsory HIV testing, and therefore fulfil its international obligations on human rights.

1. Расширение тестирования и консультирования на ВИЧ как обязательный компонент мероприятий по обеспечению всеобщего доступа к профилактике, лечению, уходу и поддержке при ВИЧ-инфекции в Европейском регионе ВОЗ: Основы политики [Электронный ресурс]. – Режим доступа: <http://www.who.int/hiv/pub/vct/>

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Тарас М.В.

Право на необмежений доступ до добровільного і конфіденційного або анонімного тестування на ВІЛ: міжнародно-правові аспекти

Проаналізовано міжнародно-правові аспекти реалізації права на необмежений доступ до добровільного і конфіденційного або анонімного тестування на ВІЛ, що є елементом права кожної людини на найвищий досяжний рівень фізичного і психічного здоров'я.

Висвітлено формальні вимоги до захисту права на необмежений доступ до добровільного, конфіденційного або анонімного тестування на ВІЛ. Тестування на ВІЛ повинно супроводжуватися якісними консультаванням і супутніми послугами. Кожна людина повинна мати можливість прийняти добровільне й усвідомлене рішення, пройти чи ні тестування на ВІЛ. Медичні працівники повинні забезпечити пацієнтів мінімальною інформацією з тим, щоб отримати їхню інформовану згоду. Довільне, обов'язкове чи примусове тестування на ВІЛ заборонене як таке, що порушує етичні принципи й основні права людини і є безрезультатним в інтересах суспільної охорони здоров'я. Право на свободу від недобровільного тестування на ВІЛ ґрунтується на таких міжнародно гарантованих правах, як право на здоров'я, право на свободу, безпеку і недоторканність особи і право на свободу від медичних і наукових експериментів без добровільної згоди, яке є похідним від заборони катувань та інших жорстоких, нелюдських або таких, що принижують гідність, видів поводження і покарання.

Проте довільне, обов'язкове чи примусове тестування на ВІЛ застосовується в багатьох країнах. Саме тому існує необхідність удосконалення норм національних законодавств у цій сфері. Також наголошується на формуванні на основі чинних норм міжнародного права, практики міжнародних організацій та органів прав людини міжнародного стандарту поводження з людьми, що живуть з ВІЛ/СНІД. Згідно з цим стандартом, держави повинні забезпечити право на необмежений доступ до добровільного, конфіденційного або анонімного тестування на ВІЛ.

Ключові слова: права людей, які живуть з ВІЛ/СНІД, тестування на ВІЛ, інформована згода, право на здоров'я.

Тарас М.В.

Право на неограниченный доступ к добровольному и конфиденциальному или анонимному тестированию на ВИЧ: международно-правовые аспекты

Проанализированы международно-правовые основы реализации права на неограниченный доступ к добровольному, конфиденциальному или анонимному тестированию на ВИЧ, являющемуся элементом права каждого человека на наивысший достижимый уровень физического и психического здоровья.

Освещены формальные требования по защите права на неограниченный доступ к добровольному, конфиденциальному или анонимному тестированию на ВИЧ. Тестирование на ВИЧ должно сопровождаться качественными предварительным и посттестовым консультированием и сопутствующими услугами. Каждый человек должен иметь возможность принять добровольное и осознанное решение, пройти или нет тестирование на ВИЧ. Медицинские работники должны обеспечить пациентов минимальной информацией с тем, чтобы получить их информированное согласие. Произвольное, обязательное или принудительное тестирование на ВИЧ запрещено как нарушающее этические принципы и основные права человека и безрезультатное в интересах общественного здравоохранения. Право на свободу от недобровольного тестирования на ВИЧ основывается на таких международно гарантированных правах, как право на здоровье, право на свободу, безопасность и неприкосновенность личности и право на свободу от медицинских, научных или иных опытов без добровольного согласия, являющееся производным от права на свободу от пыток и других жестоких, бесчеловечных или унижающих человеческое достоинство видов обращения или наказания.

Тем не менее произвольное, обязательное или принудительное тестирование на ВИЧ продолжает применяться во многих странах. Именно поэтому существует необходимость дальнейшего совершенствования норм национальных законодательств в данной сфере. Также подчеркивается важность формирования на основании действующих норм международного права и практики международных организаций и органов по правам человека международного стандарта обращения с людьми, живущими с ВИЧ/СПИД. Согласно этому стандарту, государства должны гарантировать право на неограниченный доступ к добровольному, конфиденциальному или анонимному тестированию на ВИЧ.

Ключевые слова: права людей, живущих с ВИЧ/СПИД, тестирование на ВИЧ, информированное согласие, право на здоровье.