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## **REPORT WITH RECOMMENDATION**

*Ex officio*

**Case no. 305/2019**

**regarding  
the treatment of persons with HIV and AIDS in Kosovo**

May, 2019



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To: Mr. Uran Ismaili, Minister of the Ministry of Health  
Mr. Basri Sejdiu, Director-General of Kosovo Hospital and Clinical Services  
Mrs. Ardita Baraku, Chief Inspector of the Health Inspectorate

Copy to: Mr. Habit Hajredini, Director of the Office for Good Governance

Prishtina, 15 May 2019

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**The views described herein are the views of the institution, respondents, participants in the interviews and focus groups and do not represent the views or opinions of the Global Fund to Fight AIDS, Tuberculosis and Malaria, nor is there any approval or authorization of this material, express or implied, by the Global Fund to Fight AIDS, Tuberculosis and Malaria”.**

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## Purpose of the Report

1. The protection of human rights and fundamental freedoms is essential and very important for an effective response to the prevention and treatment of HIV<sup>1</sup> in Kosovo. Despite the fact that Kosovo has made a lot of progress in responding to HIV and AIDS, there are still aspects that require attention of responsible authorities with regard to the rights of persons affected by HIV and AIDS. They continue to face challenges, especially in testing and access to prevention, treatment, health care and other services related to HIV and AIDS. These challenges are also related to economic barriers, prejudices and stereotypes, gender inequality and the presence of stigma and discrimination in health institutions.
2. Firstly, this Report aims to assess the application of HIV testing and counselling standards at country level, more specifically, the assessment of the application of key principles during HIV testing, namely: consent, confidentiality, counselling, accuracy of test results and connection/linkage to prevention, care and treatment services for HIV. Secondly, this Report aims to assess the effective realization of the rights of persons with HIV living in Kosovo with regard to access to care and treatment, focusing particularly on discrimination, inequality, failure to protect rights and treatment of children living with HIV.<sup>2</sup>
3. These rights, protected by the Constitution and international instruments, are implemented in practice through laws, policies and strategies, the implementation of which will be analysed by this Report, which ends with findings and recommendations regarding the improvement of the situation of people living with HIV from a human rights perspective.

## Competencies of the Ombudsperson

4. The Constitution of the Republic of Kosovo (hereinafter: the Constitution), in Article 132, paragraph 1, defines: “*The Ombudsperson monitors, defends and protects the rights and freedoms of individuals from unlawful or improper acts or failures to act of public authorities*”, whereas in paragraph 3, it defines: “*Every organ, institution or other authority exercising legitimate power of the Republic of Kosovo is bound to respond to the requests of the Ombudsperson and shall submit all requested documentation and information in conformity with the law.*”
5. According to the Law no. 05/L-019 on Ombudsperson, the Ombudsperson, inter alia, has the following competencies and responsibilities:
  - ‘*to draw attention to cases when the institutions violate human rights and to make recommendation to stop such cases and when necessary to express his/her opinion on attitudes and reactions of the relevant institutions relating to such cases.*’ (Article 18, par. 1, subpar. 1.2).

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<sup>1</sup> Acquired Immunodeficiency Syndrome which is the worst phase of HIV infection.

<sup>2</sup> Meetings held on 8 January 2019 and 15 March 2019, which were attended also by the Ombudsperson representative.

- “*to make recommendations to the Government, the Assembly and other competent institutions of the Republic of Kosovo on matters relating to promotion and protection of human rights and freedoms, equality and non-discrimination.*” (Article 18, par. 1, subpar. 5).
- “*to publish notifications, opinions, recommendations, proposals and his/her own reports.*” (Article 18, par. 1, subpar. 6).
- “*to recommend promulgation of new Laws in the Assembly, amendments of the Laws in force and promulgation or amendment of administrative and sub-legal acts by the institutions of the Republic of Kosovo.*” (Article 18, par. 1, subpar. 7).
- “*to prepare annual, periodical and other reports on the situation of human rights and freedoms, equality and discrimination and conduct research on the issue of human rights and fundamental freedoms, equality and discrimination in the Republic of Kosovo.*” (Article 18, par. 1, subpar. 8).
- “*to recommend to the Assembly the harmonization of legislation with International Standards for Human Rights and Freedoms and their effective implementation.*” (Article 18, par. 1, subpar. 9).

By submitting this Report to the competent institutions and upon its publication, the Ombudsperson intends to carry out these constitutional and legal responsibilities.

### **Description of the case**

6. This report was initiated ex-officio by the Ombudsperson based on discussions<sup>3</sup> made in meetings of the advocacy group<sup>4</sup> of the HIV prevention program, consultative meeting with organizations working in the field of rights of persons with HIV in Kosovo, the Ombudsperson report on reproductive health<sup>5</sup>, as well as findings by ex-officio investigations conducted, related to this report.

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<sup>3</sup> Meetings held on 8 January 2019 and 15 March 2019, which were attended also by the Ombudsperson representative.

<sup>4</sup> The HIV Program in Kosovo is focused on HIV prevention and, among other things, seeks to strengthen and develop adequate policies and joint advocacy between stakeholders, civil society and relevant government structures. This program, within the Coordination Mechanism for HIV and TB, has established a technical group known as the Programme Advocacy Group (PAG), consisting of representatives of people living with HIV and key populations (Men who have sex with men, injecting drug users and sex workers), public, governmental and non-governmental institutions and international institutions that will work in relation to legal, regulatory or cultural barriers to the development of effective interventions. The PAG has started its work in mid-2017, and so far a series of meetings and workshops with its representatives are held in order to push ahead of the group's agenda, focusing on improving services for key populations, legal gaps, stigma reduction and discrimination related to HIV.

<sup>5</sup> Ombudsperson Institution, Sexual and Reproductive Health and Rights in Kosovo: A Reality Beyond the Law, December 2016, accessible to: <https://www.oik-rks.org/2016/12/08/raporti-te-drejtat-ne-shendetin-seksual-dhe-riprodhues-ne-kosove-nje-realitet-pertej-ligjit/>.

## **Actions of the Ombudsperson Institution**

7. On 8<sup>th</sup> of April 2019, the representatives of the Ombudsperson Institution (OIK) met with the Director of the Infectious Disease Clinic (IDC) in Prishtina to receive information regarding the treatment and access to services of persons with HIV and AIDS. But the Director of the IDC, with an unfitting behaviour, refused to provide information to OIK representatives on the grounds that they should first appear at the Patients' Rights Office, and after obtaining their consent, they should make an appointment with the Director of the IDC.
8. Subsequently, the OIK representatives met with the Head of the Ward A, where patients with HIV and AIDS and with febrile conditions, are treated. There they obtained information that this ward has 22 beds, while these patients were treated by three infectologists and eight nurses, providing 24-hour services. They explained that they currently treat and supervise 35 HIV-infected patients, out of which 5 are women and a minor child of 13 years of age. They pointed out that there are two patients in this ward who are being treated for about 20 years, while the vast majority of others receive the therapy at home, whereas 5 of them refuse to be treated and currently only three patients are hospitalized in this ward; one of them is a prisoner. During the conversation, the Head of Ward A stated that in the period when the ward was overloaded by seasonal flu patients, room no.2 was made available for use (where patients with HIV and AIDS are treated) and was placed in corridors, but this condition lasted only one week and during that time none of the patients with HIV was treated. He stressed that the results of CD4 and Viral Load test scores were communicated verbally to patients in order to safeguard confidentiality. He stressed that malfunctioning of testing equipment for these tests is causing many difficulties in tracking the patient's condition. He also stressed that there are no HIV-infected pregnant women treated in this department, adding that they had difficulties in treating a HIV-infected minor, as there was no pediatric ARV treatment (therapy) for HIV-infected children, but he needed to be treated with therapy for adults. Head of Ward A stated that this case raised concerns since the parents and siblings of the minor are HIV negative. According to him, the minor was interviewed by the child psychologist who found no abusive elements from which he could have been infected. But also, in the early stages, the minor was treated with two or three doses of blood and blood products in the ORL wards, but expressed no doubt that he could have been infected as a result of the blood transfusion, as according to him, blood is tested before transfusions. Finally, the head of Ward A stressed that his ward needs a clinical psychologist to provide psycho-social treatment to HIV infected and AIDS patients, as well as provide additional inventory and semi-invasive monitor in room no. 2, where HIV-infected and AIDS patients are treated.
9. The OIK representatives met with one of the anaesthesiologists of Anaesthesiology Clinic to verify that patients undergoing planned (elective) surgery at the Surgical Clinic in Prishtina are obliged, regardless of their willingness, in addition to general analysis (*Se, Hemogram, Leukocyte Formula, Time of Bleeding and Coagulation,*

*Glycemia, Urea, Creatinine, Hepatogram, Transaminases, Alkaline Phosphatase, GT Range, Urine)* to undergo the HIV, HBsAg and HCV tests. During the conversation, the anaesthesiologist acknowledged that the patient is not given permission to undergo surgery if not equipped with abovementioned analysis and, as evidence, provided us with a form of laboratory analysis of one of the surgical clinics, whereby *inter alia* was written: “*Without complete analysis, the patient is not given permission to undergo surgery*”; and according to him, the clinic is violating patients' rights for compulsory treatment and that this action of health authorities is ungrounded and unjustifiable. The same goes for the Gynaecology/ Obstetric Clinic of HUCSK. All pregnant women, who undergo caesarean birth, are instructed to perform these three tests before surgery. This is done to protect the medical staff. However, preventing mother-to-child transmission of infection must start very early in order to ensure that an HIV positive mother will give birth to an HIV negative child. If the test is made a few days before delivery, this cannot be prevented. Based on information from field professionals in operational teams, it is said that the same practice is followed by private institutions in Kosovo.

10. On the same day, the OIK representatives held a joint meeting with the Director of the National Institute of Public Health (NIPH) and the Head of the Department of Microbiology with whom they discussed about blood tests (CD4 and Viral Load) for HIV and AIDS infected patients in Kosovo. They stated that by means of Decision No. 06/14 of the Minister of Health (MoH) of 16 January 2014, from 2014 onwards, Tuberculosis and HIV laboratories at the NIPH have been designated as reference laboratories for Tuberculosis Diagnostics and HIV, in Kosovo, without creating the necessary preconditions and without increasing the number of staff. They stressed that during 2018, 1258 blood samples were tested with "ELISA" analysis (*enzyme-linked immunosorbent assay*) IV generation, and only 7 of them resulted as positive<sup>6</sup>. While during 2019, 351 blood samples were tested and 4 of them were positive. With regard to collaboration with private laboratories and reporting of cases with HIV and AIDS to the NIPH, they explained that they have no information of any licensed laboratories, hence there might be cases of persons infected and unreported. They said they had problems with the functioning of CD4 and viral load analysis test equipment, and difficulties in supplying reagents and also reported that *the Flowcytometer FASCount BD* for the measurement of CD4 cells of HIV infected persons was out of service since December 2018, and the same was made functional on 4 February 2019. They also stated that during this period, 5 or 6 patients left without CD4 analysis results. Regarding the *COBAS 4800*, used for Viral Load tests, they stated that it was a defect with the adapter and after consultations with persons responsible within the NIPH; the replacing parts were provided and paid from the NIPH's servicing budget. They promised that this equipment will be made functional over the next few days, but for now they need kits<sup>7</sup> to carry out tests on both equipment, and the request for

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<sup>6</sup> Each person suspected of HIV by the Rapid Test, then he/she must be tested with the ELISA test, and if the result is positive, it should be confirmed by another specific test.

<sup>7</sup> Relevant reagent for CD4 and Viral load.

providing kits for measuring HIV viral load, as well as kits for measurement of CD4 cells in HIV-infected persons, are sent to the MoH and they are waiting for their supply.

11. On 12 April 2019, the OIK's representative held a joint meeting with the Head of the Public Health Division in the Ministry of Health (MoH) and the coordinator of the HIV program in the Ministry of Health, with whom they discussed the issue of HIV and AIDS in Kosovo. They stated that funding related to HIV/AIDS in Kosovo is performed exclusively by the MoH, referring to diagnosis and treatment of these patients. According to them, by 2017, the blood samples of the patients in Kosovo, regarding the CD4 and viral load, were sent for analysis to the laboratories in France, and after this period, the same are performed in the laboratories of NIPH. They asserted that MoH does not have separate budget lines regarding funding programs for HIV and AIDS in Kosovo, but financial resources are allocated to the MoH budget as needed and, as a result of this situation, they often encounter difficulties in providing medicines and reagents for equipment that perform CD4 and Viral Load analysis. They stated that the Kosovo HIV Committee is functional, while Kosovo Councils of Clinical Guidelines and Protocols, with the support of the United Nations Population Fund (UNFPA), during 2018 issued the Guideline no.4, titled: "*Guideline on HIV testing services*". Regarding HIV testing in private institutions, they reported that this test can be performed in numerous private institutions in the Republic of Kosovo, but were unable to specify which of them perform these tests (rapid tests) and report to NIPH in the event of identifying an HIV positive case, in accordance with the legislation. They reported that there is a Voluntary Testing Centre within the Infectious Disease Clinic and that during 2018, 332 persons (205 males and 127 females) were tested, of whom 6 resulted to be HIV positive, while based on statistics of this centre, no information on testing of pregnant women and children was processed. Regarding the provision of ARV therapy for children, they stated that no such medicines are foreseen in the essential list, noting that there were no children subject to the therapy in the past and that the case of the minor "*constitutes an exception*". According to them, the inclusion of drugs on the essential list is done according to the requirements of the health authorities of the respective fields, adding that the supply of health articles and reagents is done according to the plans of health institutions. They did not hesitate to convey the responsibility for expenses of kits without coverage to the NIPH, stating that the MoH supplied sufficient quantities of them and in compliance with the requirements of NIPH, but they were not able to manage the situation in a proper way so they are now facing the consequences. They asserted that the MoH had a three-year contract with the economic operator for supplying kits for CD4 and Viral Loads, but the NIPH exceeded the allowed value for the product, therefore, after being notified by the NIPH for non-functioning of equipment as a result of lack of reagents, MoH announced a tender for supply of kits and the same was closed on 4<sup>th</sup> of April 2019, but no bidders were submitted. The OIK representative informed them about the situation created in the Surgical Clinics regarding compulsory patient testing before undergoing elective surgery and they

were surprised about the requirements and expressed the opinion that they are unnecessary. They also announced that an Administrative Instruction (no. 01/2019) on the Activity, Structure and Functions of Health Services for HIV/AIDS was drafted, which replaces the Administrative Instruction no. 02/2011) on the Activity, Structure and Functions of Health Services for HIV/AIDS. However, the need to draft a Guideline/Protocol for treatment and management of HIV cases and standard action procedures is felt.

12. On the same day, the OIK's representatives met with the Deputy Chief Inspector of the Health Inspectorate with whom they discussed eventual complaints regarding HIV/AIDS cases in Kosovo. She informed that the Chief Inspector was on official duty abroad and had no information regarding possible complaints of such nature, whether testing, treating or violating the confidentiality of HIV-infected patients, except a case reported years ago in the inspectorate regarding the suspicion that a woman had serious health complications as a result of blood/transfusion treatment. She promised that as soon as the Chief Inspector returns, she will give us the correct information that the Health Inspectorate possesses.
13. On the same day, the OIK's representatives met with the Director of the Public Relations Department within the State Agency for Protection of Personal Data, which has the legal responsibility for overseeing the implementation of the rules for protection of personal data. During the conversation, the OIK's representatives asked questions regarding any case of HIV/ AIDS infected persons addressed by this agency, in terms of issuing decisions on submitted complaints, inspections and controls, public information, and promoting support of fundamental rights to the protection of personal data, which are part of the main scope of work within the Agency's mission. He informed that, at least till now, the Agency did not have any submitted complaints and informed that there are employees in HUCSK dealing with the Protection of Personal Data and the same have close cooperation with the Agency. He explained that during 2018, the Agency organized information campaigns with health employees in 7 general regional hospitals in Kosovo and they were closely informed of their duties and responsibilities, specifying that they should sign the statements of confidentiality and the statements are stored in their files, and when it comes to the privacy of the patient, he/she must give written consent regarding access to this information. He informed that the Agency is currently in the process of restructuring, in accordance with the new law on personal data protection, which was published in the Official Gazette on 25 February 2019.
14. On 25<sup>th</sup> of April 2019, a focus group was held with a responsible institutions and non-governmental organizations dealing with issues of HIV-infected persons and key populations, where there was a productive discussion of the current situation for access to services and treatment of persons with HIV, the challenges faced by these people, and the actions that need to be taken to improve the situation in the future.

## **Legal basis**

15. Article 21, paragraphs 2 and 3 of the Constitution of the Republic of Kosovo (hereinafter referred to as the *Constitution*) defines the following: “*The Republic of Kosovo protects and guarantees human rights and fundamental freedoms as provided by this Constitution, Everyone must respect the human rights and fundamental freedoms of others.*”
16. Article 22 of the Constitution defines: “*Human rights and fundamental freedoms guaranteed by the following international agreements and instruments are guaranteed by this Constitution, are directly applicable in the Republic of Kosovo and, in the case of conflict, have priority over provisions of laws and other acts of public institutions*” while Article 23 defines: “*Human dignity is inviolable and is the basis of all human rights and fundamental freedoms.*”
17. Whereas in Article 24 of the Constitution guarantees equal treatment. It defines the following: “*All are equal before the law [and] No one shall be discriminated against on grounds of race, colour, gender, language, religion, political or other opinion, national or social origin, relation to any community, property, economic and social condition, sexual orientation, birth, disability or other personal status.*”
18. Article 26 of the Constitution guarantees the right to personal integrity. It defines: “*Every person enjoys the right to have his/her physical and psychological integrity respected, which includes:*  
[...]  
(2) *the right to have control over her/his body in accordance with law;*  
(3) *the right not to undergo medical treatment against his/her will as provided by law.*”
19. Article 36, paragraph 1 of the Constitution defines: “*Everyone enjoys the right to have her/his private and family life respected, the inviolability of residence, and the confidentiality of correspondence, telecommunication and other communication.*”, while the Article 53 defines: “*Human rights and fundamental freedoms guaranteed by this Constitution shall be interpreted consistent with the court decisions of the European Court of Human Rights.*”
20. The Constitution makes a number of instruments and international agreements in the field of human rights, directly applicable in the Kosovo legal order. It is stipulated that these acts are *directly applied in the Republic of Kosovo and prevails in case of conflicts, against the provisions of laws and other acts of public institutions, including the European Convention for the Protection of Human Rights and Fundamental Freedoms and its Protocols.* Paragraph 1 of Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (hereinafter referred to as the Convention) defines: “*Everyone has the right to respect for his private and family life, his home and his correspondence*”.
21. Paragraph 1 of Article 4 of Law no. 04 / L-125 on Health defines: “*Implementation of this law shall be in full compliance with the human dignity, fundamental rights*

*and freedoms set by the Constitution of the Republic of Kosovo, international covenants and legislation guaranteed by the Constitution and directly implemented in the Republic of Kosovo.”; while paragraph 5 of this Article defines: “The rights and responsibilities of the citizens, residents, and other healthcare users are regulated by the Law on rights and responsibilities of citizens in healthcare.”*

22. Paragraph 1 of Article 5 of Law no. 04/L-125 on Health defines: “*The provision of healthcare is based on the following principles.*” While paragraph 1.2 defines: “*inclusiveness and non-discrimination: equal healthcare for all citizens and residents by ensuring the standards during fulfilling the needs at all levels of healthcare as well as ensuring healthcare without discrimination on basis of: gender, nation, race, color, language, religion, political preferences, social status, sexual orientation, the level of physical or mental abilities, family status, or age.*” While paragraph 1.3 of this Article defines: “*quality: Applying international standards in organization, development and provision of healthcare with respect to all aspects including: patient focused treatment, resources use, organization of: work, training, education, licensing, accreditation, ethical guidelines, and protection of interests of users of healthcare services.*”
23. Paragraph 1 of Article 13 of Law no. 04 / L-125 on Health defines: “*Healthcare shall be implemented through the following measures and actions [...] prevention and early detention and treatment of drug addictions, sexually transmitted diseases, and HIV infection.*” While Article 24 obliges: “*In cases when the healthcare institution is unable to provide healthcare within its scope, it is obliged to refer the citizen to other healthcare institutions able to treat the particular case accompanied with respective medical documentation, while respecting the referral system, from paragraph 3 Article 16 of this law.*”
24. Paragraph 2 of Article 52 of Law no. 04/L-125 on Health defines: “*Healthcare institution from paragraph 1 of this Article is responsible for regular and safe, collection, storing, and management of the data, provision of the easy access to data, protection and confidentiality of the personal data, and protection of data from abuse, in compliance with the legislation in power.*”; and: “*Health professional and healthcare institution shall report their services [...]ensuring professional confidentiality<sup>8</sup>, in compliance with the law.*”
25. Paragraph 1 of Article 3 of Law for Prevention and Fighting against Infectious Diseases defines: “*The infectious diseases in the sense of this Law where their prevention and prohibition is in the interest of our country are as follows: [...] B 20 - B24, HIV infections, AIDS [...].*” While Article 10 defines: “*In order to timely detect the infection sources and its ways of transmission, the health institutions shall perform the following: [...] Presence examination of the hepatitis markers B and C, HIV virus and syphilis for the voluntary blood donors [...].*” While paragraph 2 of Article 27 defines: “*Persons who are bearers of hepatitis B and C and HIV anti-gents*

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<sup>8</sup> Law no. 04 / L-125, Article 3 (Definitions), paragraph 1.33: **Professional confidentiality** - keeping confidential the data about the health status of the healthcare user from unauthorized access.

*must receive strict professional information relating to their behaviour and actions in order not to spread such a disease.”*

26. Paragraph 1 of Article 2 of Law no. 2004/38 on the Rights and Responsibilities of the Citizens in the Health Care defines: “*Every citizen is entitled to the health care that is conditioned by his state of health. The health care should be adequate and continuously accessible to all without discrimination.*” While paragraph 5 of this Article defines: “***Health care is provided without any discrimination, if, in the course of the medical treatment citizens are not discriminated on the basis of their social position, political views, origin, nationality, religion, gender, sexual preferences, age, marital status, physical or mental disability, qualification or on any other grounds [...].***”
27. Paragraph 1 of Article 6 of Law no. 2004/38 on the Rights and Responsibilities of the Citizens in Health Care defines: “***In the course of medical treatment, the citizen's human dignity, privacy, personal integrity and religious beliefs shall be respected***” while paragraph 2, of this Article defines: “*In the absence of provisions in this Law to a different effect, only the interventions necessary for the health care of the citizen may be performed on a citizen, without his consent.*”
28. Paragraph 1 of Article 9 of Law no. 2004/38 on the Rights and Responsibilities of the Citizens in Health Care defines: “*The citizen is entitled to receive full information in an individualized form*”; while paragraph 2 defines: “*The citizen is entitled to receive detailed information on: a) His state of health, including its medical evaluation (...); b) The success or failure of the medical treatment, upon completion of each examination and intervention, including if the result deviated from what was expected, and the reasons for this [...].*”
29. Paragraph 1 of Article 20 of the Law no. 2004/38 on the Rights and Responsibilities of the Citizens in Health Care defines: “*The citizen has the right to protection of the confidentiality and secrecy of his personal data and information related to his state of health and medical treatment, as well as to any other information included in his health documentation*”; while paragraph 2 defines: “*A citizen is entitled to make a statement as to who may receive information on his illness and the expected outcome thereof and who is not entitled to be fully or partially acquainted with his health care data.*”
30. Law No. 06/L-082 on Protection of Personal Data, Article 3, paragraph 1, subparagraph 1, stipulates: “***Personal Data***- any information related to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified directly or indirectly, particularly by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person;” whereas, subparagraph 4 of paragraph 1 of the same Article, stipulates: “*Classification of Personal Data – marking of personal data to indicate their sensitive nature. Specific conditions should be set for classified data, according to which users shall be able to process them.*

*The classification should be attached to sensitive personal data until their deletion, erasure, destruction or anonymization.”; whereas, subparagraph 25 of the same paragraph and Article stipulates: “**Sensitive Personal Data** - personal data revealing ethnic or racial origin, political or philosophical views, religious affiliation, union membership or any data related to health condition<sup>9</sup> or sexual life, any involvement in or removal from criminal or offence records retained in accordance with the law. Biometric characteristics are also considered sensitive personal data if the latter enable the identification of a data subject in relation with any of the abovementioned circumstances in this sub-paragraph.” whereas, in Article 8 of the same Law, it is stipulated: “Specific categories of personal data,<sup>10</sup> should be protected in a special manner and be classified for the purpose of preventing the unauthorized access and use [...].”*

31. Article 1 of Administrative Instruction (Health) No. 02/2011 on the Activity, Structure and Functions of Health Services for HIV/AIDS stipulates: “*This Administrative Instruction regulates the organization, management, structure and operation of health services offered by health institutions to prevent, treat and control HIV/AIDS*”; whereas Article 4 stipulates: “*The Ministry of Health establishes Kosovo HIV/AIDS Committee.*”
32. Paragraph 1 of Article 5 of the Administrative Instruction (Health) No. 02/2011 on the Activity, Structure and Functions of Health Services for HIV/AIDS stipulates: “*The rights of persons living with HIV/AIDS are: 1.1 Persons living with HIV/AIDS shall receive care, support, and treatment services in accordance with best international practices.*” Whereas, paragraph 1.5 of this article stipulates: *Maintenance of Confidentiality for their HIV Infection.*”
33. Paragraph 1 of Article 15 of the Administrative Instruction (Health) No. 02/2011 on the Activity, Structure and Functions of Health Services for HIV/AIDS stipulates: “*The Testing result for HIV-positive shall be notified only to:*

  - 1.1 The tested person;*
  - 1.2 Husband, wife or cohabitating partner, parent or legal guardian when the latter is a minor or has lost his / her ability to act;*
  - 1.3 Personnel, which have the task of dealing with advice and information, about HIV positive test;*
  - 1.4 Personnel caring for and treating the infected person in health institutions, rehabilitation institutions, residential social care, prisons or detention centres.”*

34. Article 1 of Administrative Instruction 15/2013 Charter of Patient Rights and Responsibilities, stipulates: “*With this Administrative Instruction is defined the*

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<sup>9</sup> Article 3, paragraph 1.21, defines the following health data: “*Data Concerning Health - personal data related to physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.*”

<sup>10</sup> According to Article 8, paragraph 1, of this Law, special data categories also include health data.

*obligation of health institutions and health professionals to respect the rights of patients.”*

35. Article 1 of Administrative Instruction (MoH) No. 08/2015 on Clinical Guidelines and Protocols, stipulates: “*Through this Administrative Instruction are established and defined organizational structure, tasks, the composition of administrative bodies, deadlines for drafting, revision and revocation of the clinical Guidelines and protocols in the territory of the Republic of Kosovo in order to improve the quality and safety of health services.*”

## **International standards**

36. This section will focus on international practices and standards related to the topics covered by this Report on the Treatment of HIV / AIDS from the Human Rights Perspective.
37. From the very outset it should be noted that it is generally accepted that, in international human rights law, HIV/AIDS raises many issues related to human rights. The general (no discrimination) access to healthcare and treatment is an important component of the right to health for people living with HIV/AIDS.<sup>11</sup> In general, human rights and public health share the same objective for promoting and protecting the right to welfare of all individuals.<sup>12</sup> The Vienna Declaration and Action Program, approved by the World Conference on Human Rights in 1993, confirmed that all human rights are universal, indivisible, interdependent and interrelated.<sup>13</sup>
38. According to the Joint United Nations Program on HIV/AIDS (UNAIDS)<sup>14</sup>, the key human rights principles that are essential for an effective response of states to HIV can be found in several international instruments: 1) Universal Declaration of Human Rights; 2) European Convention on Human Rights and Fundamental Freedoms and its Protocols; 3) the International Covenant on Civil and Political Rights and its Protocols; 4) Council of Europe Framework Convention for the Protection of National Minorities; 5) Convention on the Elimination of All Forms of Racial Discrimination; 6) Convention on the Elimination of All Forms of Discrimination against Women; 7) Convention on the Rights of the Child; 8) Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; 9) International Covenant on Economic, Social and Cultural Rights, 10) Regional Instruments ([....] American Convention on Human Rights, Karta The African Charter on Human and Peoples' Rights).<sup>15</sup> Moreover, a significant

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<sup>11</sup> United Nations and World Health Organization, Right to Health, Fact Sheet no.31, accessible at: [https://www.ohchr.org/Documents/Publications/Factsheet\\_31.pdf](https://www.ohchr.org/Documents/Publications/Factsheet_31.pdf), pg. 21.

<sup>12</sup> Office of the United Nations High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, International Guidelines on HIV/AIDS and Human Rights, 2006, fq. 77.

<sup>13</sup> A/CONF.157/24 (Part I), chap. III.

<sup>14</sup> Office of the United Nations High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, International Guidelines on HIV/AIDS and Human Rights, 2006, page. 78

<sup>15</sup> It should be reminded that acts ranging from one to eight are directly applicable in Kosovo, in accordance with Article 22 of the Constitution.

number of conventions, declarations that, in particular or in general, recognize and protect the human rights of persons living with HIV are adopted.<sup>16</sup>

### **International Guidelines on HIV/AIDS and Human Rights<sup>17</sup>**

39. In 1996, the Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Program on HIV/AIDS (UNAIDS) has published for the first time the International Guidelines for HIV/AIDS and Human Rights. This document has been revised and the latest version of these guidelines has been published in 2006. The purpose of these guidelines is to help States translate the norms of international human rights law into practical implementation in the context of HIV-infected persons.
40. This document establishes twelve (12) Guidelines for states to respect, protect and promote the rights of persons living with HIV. For the purposes of this Report, we will only mention some of them<sup>18</sup>:
  - **GUIDELINE 1:** *States should establish an effective national framework for their response to HIV which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV policy and program responsibilities across all branches of government.*
  - **GUIDELINE 5:** *States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies.*
  - **GUIDELINE 6 (as revised in 2002):** *States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of quality prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price.*

<sup>16</sup> London Declaration on AIDS Prevention, World Summit of Ministers of Health, 28 January 1988; Paris Declaration on Women, Children and AIDS, 30 March 1989; Recommendation on the Ethical Issues of HIV Infection in the Health Care and Social Settings, Committee of Ministers of the Council of Europe, Strasbourg, October 1989 (Rec. 89/14); Council of Europe, Committee of Ministers, Recommendation R(87) 25 to member States concerning a common European public health policy to fight AIDS, Strasbourg, 1987; European Union, European Parliament and Council Decisions on “Europe Against AIDS” programme (including Dec. 91/317/EEC and Dec. 1279/95/EC); Declaration of Basic Rights of Persons with HIV/AIDS, Organizing Committee of the Latin American Network of Community-Based Non-Governmental Organizations Fighting AIDS, November 1989; Declaration of the Rights of the People with HIV and AIDS, United Kingdom, 1991; Australian Declaration of the Rights of People with HIV/AIDS, National Association of People Living with HIV/AIDS, 1991; Prague Statement, Pan-European Consultation on HIV/AIDS in the Context of Public Health and Human Rights, November 1991;

<sup>17</sup>Office of the United Nations High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, International Guidelines on HIV/AIDS and Human Rights, 2006

<sup>18</sup> Other guidelines are available at: Office of the United Nations High Commissioner for Human Rights and Joint United Nations Programme on HIV/AIDS, International Guidelines on HIV/AIDS and Human Rights, 2006, from page 17 to 19.

*States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive, curative and palliative care [...]*

*States should take such measures at both the domestic and international levels, with particular attention to vulnerable individuals and populations.*

- **GUIDELINE 8:** *States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.*
- **GUIDELINE 10:** *States should ensure that Government and the private sector develop codes of conduct regarding HIV issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.*

## **World Health Organization: Consolidated Guidelines on HIV Testing Services**

41. These guidelines were published<sup>19</sup> by the World Health Organization (WHO) in 2015. The document provides relevant existing guidelines on the provision of HIV Testing Services and addresses the issues and elements for their effective provision and for being identical in different social contexts and populations.
42. We will further summarize some of the key obligations that these guidelines recommend for states in order to bring their policies and practices in line with WHO's objectives in this field.

- **Services Prior to HIV testing**

This section of the manual deals with essential services prior to testing and testing. Some basic services should be offered before testing in all cases, regardless of the approach chosen for HIV testing services. The activities / obligations that emerge for states in this section are as follows<sup>20</sup>:

1. Promotion of HIV Testing Services.<sup>21</sup>
2. Creating an Enabling Environment:<sup>22</sup> *WHO, in this regard, recommends that there should be initiatives to establish and enforce privacy protection and to establish practices, policies and laws to prevent discrimination and*

<sup>19</sup> World Health Organization, Consolidated guidelines on HIV testing services, accessible at: <https://www.who.int/hiv/pub/guidelines/hiv-testing-services/en/>

<sup>20</sup> Having in mind that some of them are self-explanatory by their name, we will stop and explain a little broader only some of these obligations.

<sup>21</sup> World Health Organization, Consolidated guidelines on HIV testing services, page 18.

<sup>22</sup> Page 20.

*to promote tolerance and acceptability for people living with HIV. This can help create environments where disclosure of HIV status is easier.*

3. Ensuring confidential setting and maintaining confidentiality:<sup>23</sup> *Confidentiality applies not only to the test results and reports of HIV status but also to any personal information. HIV testing services should avoid practices that can inadvertently reveal a client's test results, or HIV status, to others in the waiting room or in the health facility.*
4. Pre-test information.<sup>24</sup>
5. Informed consent (for testing): *Informed consent must always be obtained individually and privately from the person receiving testing. In most cases, a verbal consent is sufficient. The service provider must ensure that the client has learned enough about testing, so that he/she is able to provide the informed consent.*<sup>25</sup>

***Testing against the will or mandatory or forced testing is never permitted.***<sup>26</sup>

- **Access to service provision**

This section of the guidelines provides the following recommendations:

1. All HIV Testing Services shall have Standard Operating Protocols (hereinafter referred to as SOPs).<sup>27</sup>
2. Integration of HIV Testing Services with other services.
3. Decentralisation of the HIV testing services.
4. The use of Lay service providers for some clinical services, including counselling and referrals. Lay providers, who are trained and supervised in the use Rapid Diagnostic tests (TRD), can independently perform safe and effective HIV testing services.<sup>28</sup>

## **Priority populations**

43. The following categories are among the priority populations, which are considered vulnerable, especially in relation to access to services and HIV treatment:

- **Children**<sup>29</sup>

Given the high mortality rate in children (especially those up to one year old), WHO provides the following recommendations regarding the provision of HIV testing services in the cases of children:

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<sup>23</sup> Page 20.

<sup>24</sup> Page 20.

<sup>25</sup> Page 24.

<sup>26</sup> Page 39.

<sup>27</sup> Page 39.

<sup>28</sup> WHO, Consolidated guidelines, Page 44.

<sup>29</sup> Page 60 – 62.

1. All HIV-exposed infants have HIV virological testing at four to six weeks of age or at the earliest opportunity thereafter.
2. Well HIV-exposed infants undergo HIV serological testing at around nine months of age (or at the time of the last immunization visit).
3. Children over the age of 18 months, suspected of HIV infection, or exposure to HIV, are recommended to undergo serological testing [...].
4. It is recommended that infants with signs or symptoms suggestive of HIV infection undergo HIV serological testing and, if reactive, should be referred for virological testing.
5. Children of school age (6–12 years old) should be told their HIV-positive status.

- **Pregnant women**

Concerning pregnant women, *WHO recommends the provision of HIV testing services for pregnant women through the PITC method*<sup>30</sup>. In high prevalence settings WHO recommends couples and partner HIV testing for all pregnant women and their partners. [...] *In low prevalence settings, WHO recommends couples and partner HIV testing for pregnant women from key populations and for the partners of women diagnosed with HIV.*<sup>31</sup>

## Key populations

44. In regards to key populations, WHO recommends:

1. HIV testing services should be routinely offered to all key populations.
2. Couples and partners should be offered HIV testing services with support for mutual disclosure (of HIV status, if the result is positive).
3. HIV testing services should be voluntary in all cases.

## Legal analysis

45. The constitution, as the highest legal act of a country, safeguards and guarantees the fundamental human rights and freedoms, therefore the implementation and practical realization of these rights is of interest for the functioning of the rule of law. Constitutional guarantees serve to protect human dignity and the rule of law. The Constitution, Article 21, expressly lays down the obligation of all bodies to respect the freedoms and rights of others, and therefore this principle is imperative and must be respected by all, including healthcare institutions.

46. The Constitution, in Article 25, paragraph 1, stipulates: “*Every individual enjoys the right to life*”. This paragraph clearly shows that a citizen’s right to life is at the core of the constitutional system for the protection of human rights and the right to life (its inviolability) is an absolute human right, which cannot be limited under

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<sup>30</sup> Program of Infant/Toddler Care (Programi për Kujdes ndaj foshnjës/fëmijës)

<sup>31</sup> WHO, Consolidated guidelines, page 65.

any circumstances, and no deviation from this right is allowed. The Ombudsperson notes that the Constitution clearly defines that each person enjoys the right to have his/her physical and psychological integrity respected, which among other things, when it comes to the right to personal integrity, health and right to life, the state has a positive obligation to undertake all measures to protect the inviolability of the physical and health integrity of persons, especially when integrity and human life is at stake. The Constitutional Court of the Republic of Kosovo, in the Judgment KI. 41-12, found that there was a violation of the right to life in cases where the competent state authorities did not provide sufficient protection to the citizens, although this was required by the circumstances of the event. **The Constitutional Court emphasizes that the right to life is the most important right of all human rights, from which, all other rights derive and clarifies that there are positive obligations for the authorities to take preventive and operational measures to protect the lives of all those who are exposed to danger.**

47. The Ombudsperson reminds that, pursuant to Article 53 of the Constitution, the fundamental human rights and freedoms guaranteed by this Constitution are interpreted in accordance with the decisions of the European Court of Human Rights (hereinafter referred to as the European Court).
48. In this regard, human rights-based approach toward persons with HIV/AIDS has been clarified in the case of *Kiyutin v. Russia*, which for the first time enabled the European Court to deal with the interrelationship between statuses HIV/AIDS and the European Convention on Human Rights. In this case, the European Court was asked to apply the principle of the prevention of discrimination in conjunction with Article 8 of the European Convention, which concluded: "*The Court therefore considers that people living with HIV are a vulnerable group*"; and also that HIV infection enters into "*other status*" in the text of Article 14 of the European Convention when the protected bases are listed, which potentially constitute discrimination.<sup>32</sup> Consequently, justifications regarding stigma and prejudice regarding persons with HIV / AIDS and keeping them in an unfavourable position cannot be accepted as reasonable or legitimate.
49. Article 8 of the European Convention on Human Rights guarantees the right for private and family life to be respected. In this regard, personal data protection is very important for private life and forms positive obligations for the state to protect them, especially in cases of sensitive health data. Regarding this issue, the European Court, in the Case *I v. Finland*, defines: "*Respecting the confidentiality of health data is a vital principle... this is especially valid as regards protection of the confidentiality of information about a person's HIV infection. Therefore, the state is obliged to provide practical and effective protection and to eliminate any possibility of unauthorized access to personal health data.*"

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<sup>32</sup> *Kiyutin v Russia*, ECHR, paragraphs 57 and 64

50. Article 2 of the Convention sets out the general obligations of the State to protect the right to life and includes **positive and negative aspects**: a) the **positive obligation** to protect life; and b) the **negative obligation** to refrain from unlawful taking of life. Positive obligation imposes **prevention and investigation duties**.

**Obligations of prevention** (see case *Osmani v. Great Britain*, dated 28 February 1998) obliges states' governments to prevent and combat criminal offenses. If established that governments were aware, or should have reasonably been aware at the time of the real and direct risk to the life of an identified person due to the criminal offense of a third party and **failed to take appropriate measures within their mandate**, which according to a reasonable assessment would be expected to be taken in order to avoid the risk of life, **they should be held accountable for non-compliance with the positive obligations**.

51. Article 3 of the Convention also imposes an obligation on the State that **no one shall be subjected to torture or inhuman or degrading treatment or punishment**. The convention should be understood from the point of view of its "objective and purpose", as submitted by the European Court, to protect individual human beings in the sense of the values of a democratic society, which implies that its provisions should be interpreted and applied in order to provide practical and effective protection.

52. Article 3 of the Convention contains substantive and procedural aspects, such as the obligation to investigate **prima facie** allegations of torture and other inhumane treatment. According to the case-law of the European Court, Article 3 of the Convention may be violated both by deliberate ill-treatment and by negligence or inactivity in taking specific steps or failing to ensure proper care standards. This article imposes both negative obligations and positive obligations, that is, an obligation not to commit a particular offense, and the obligation to take positive steps to ensure individuals respect their rights and protect them against maltreatment.

53. Based on the case-law of the European Court in cases of healthcare provision, it is clear that the state is obliged to provide adequate employment systems and employees capable of protecting life, for example, hospitals which should take adequate measures to protect patients' lives,<sup>33</sup> shall not deny the availability of health care (provide healthcare)<sup>34</sup> and must provide the proper (appropriate)<sup>35</sup> medicine. The court found a violation of Article 2 in the case of a child who died in an ambulance because it was not accepted by the hospital but was transferred to other institutions due to the lack of specialized equipment<sup>36</sup> and cases when due to the malfunctioning of the hospital departments resulted with lack of urgent

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<sup>33</sup> *Vo v France*

<sup>34</sup> *Cyprus v Turkey*

<sup>35</sup> *Panaitescu v Romania*

<sup>36</sup> *Asiye Genç v Turkey*

medical care, which ended up in death. Therefore, in this case as well, the court found that this act constituted a violation of Article 2<sup>37</sup>

54. Law no. 04/L-125 on Health clearly defines that the implementation of this law shall be done by respecting the dignity, fundamental human rights and freedoms defined by the Constitution of the Republic of Kosovo, international agreements and instruments guaranteed by the Constitution, which are directly applicable in the Republic of Kosovo, stipulates that the rights and responsibilities of citizens, residents and other users of health services in healthcare are regulated by the Law on the Rights and Responsibilities of Citizens in Health Care, which will be analysed in the following paragraphs of this report.
55. Article 5 of Law no. 04/L-125 on Health, in its paragraphs, sets out the basic principles based on which care in healthcare facilities should be applied, guided by the principle of inclusiveness and non-discrimination, aiming to ensure equal standards of health care for all citizens. Through this article of the Law, it is stipulates that in fulfilling citizens' requirements in providing healthcare services at all levels, health care will be provided without discrimination on grounds of sex, nation, race, colour language, religion, political beliefs, social status, sexual orientation, degree of physical and mental ability, family and age status and/or any other grounds. Similarly, the provisions of this article stipulate that citizens will be provided with quality health care and during their treatment international standards will be applied in the organization, development and provision of health care in all aspects, including: focused treatment in patients, using resources, organizing work, training, education, licensing, accreditation, ethical guidelines and protecting the interests of health service users.
56. Article 13 of the Law No. 04/L-125 on Health clearly defines the positive obligations of the health authorities, which are obliged to implement various measures and actions in the health care of citizens, depending on the situation, where *inter alia*, the prevention, early detection and treatment of addiction diseases, sexually transmitted diseases and HIV infection, are required. Furthermore, Article 24 defines cases when the health care institution is not able to provide adequate health care within its scope, the institution is obliged to refer the citizen to another healthcare facility that is able to handle the particular case, accompanying appropriate medical documentation, while respecting the referral system, as per paragraph 3 of Article 16 of this Law. Article 52 of Law no. 04/L-125 on Health, clearly defines that the health institution is the owner of data registered by them and is responsible for the collection, storage and management of data in a regular and safe manner, to ensure easy access to data, **protection and confidentiality of personal data and protection of data from misuse**, in accordance with applicable legislation.

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<sup>37</sup> See *Mehmet Şentürk and Bekir Şentürk v Turkey*

57. Law no. 02/L-109 for Prevention and Fighting against Infectious Diseases stipulates that the purpose of the law is to determine infectious diseases and to regulate activities for timely detection, evidence of occurrence, prevention, spreading prevention and their treatment. The term "*infectious disease*", according to this law, is defined as a disease caused by microorganisms and pathogenic parasites that are transmitted directly or indirectly by the sick person or the cause bearer to a healthy person as well as from animals and farming products. This law, in its Article 3, defines the list of infectious diseases, according to the International Classification of Diseases, which states that their prevention and prohibition is in the interest of our country and among other things, there are diseases classified with code B20 to B24, which are HIV / AIDS.
58. Law no. 02/L-109 for Prevention and Fighting against Infectious Diseases determines the measures to be taken in detection of the infection sources and ways of transmission of infection in due time. Therefore, health institutions are obliged to carry out the necessary actions to examine/test the presence of hepatitis B and C markers, HIV virus and syphilis on volunteer blood donors. The law also stipulates that persons who are bearers of hepatitis B and C and HIV anti-gents must receive strict professional information relating to their behavior and actions in order not to spread such a disease.
59. Law no. 2004/38 for the Rights and Responsibilities of the Kosovo Residents in the Health Care, Article 4, paragraph 1, defines the rights of each citizen for health care that is conditioned by his/her health status, stressing that health care should be adequate, with constant access for all and without discrimination; while paragraph 2 clarifies that health care is adequate if it is in compliance with ethical and professional rules, as well as with relevant guidelines of a particular health service. Based on the analysis of this case, it can be understood that the responsible authorities have failed to fulfil their legal and constitutional obligations and have committed violations, as it has been directly established that, in the present case, health care for persons infected with HIV/AIDS in Kosovo, especially regarding analysis/tests of CD4 and Viral load, was inadequate since the tests had failed several times, consequently medical treatment (ARV therapy) was not provided in line with their health condition.
60. Law no. 2004/38 for the Rights and Responsibilities of the Kosovo Residents in the Health Care, Article 20, clearly defines that a citizen has the right to protection of the confidentiality and secrecy of his personal data and information related to his state of health and medical treatment, as well as to any other information included in his health documentation, giving him/her the entitlement to make a statement as to who may receive information on his illness and the expected outcome thereof and who is not entitled to be fully or partially acquainted with his health care data.
61. According to Kosovo lawmakers, the purpose of drafting the Law no. 2004/38 on for the Rights and Responsibilities of the Kosovo Residents in the Health Care

was to define the rights and responsibilities of citizens in health care and to establish mechanisms for protection and ensuring of these rights and responsibilities. The law obliges health institutions to pay attention to the patient's health at all times, during the time he/she is in the health institutions, in accordance with ethical and professional rules. This law contains more rights in relation to the provision of health services, obliging health institutions **to respect citizens' rights** for quality health care, the right to choose a healthcare professional, the right to human dignity, the right to communication, the right to leave the institution, **the right to be informed**, the right to a personal decision, **the right to privacy**, etc. Given the above, it is obvious that, in the present case, during the health treatment of persons infected with HIV/AIDS, health institutions, failed to implement and **respect the rights and responsibilities of citizens** for quality health care in relation to the provision of health services in HIV and AIDS cases.

62. Law no. 06 / L-082 on Personal Data Protection, defines the term "*Personal Data*" any information relating to an identified or identifiable natural person (data subject); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to a name, an identification number, location data, an online identifier, or to one or more factors specific to his or her physical, physiological, mental, economic, cultural or social identity of that natural person, whereas the term "*Classification of Personal Data*" defines as a personal data entry to show their sensitive nature. The law if data are classified, conditions have to be laid down under which a user can process them. **Therefore classification has to remain with the sensitive personal data until they are deleted, erased, destroyed or anonymized**; whereas as regards the term "*sensitive personal data*" are defined any personal information revealing racial or ethnic origin, political or philosophical opinions, religious beliefs, trade-union membership or any information on health status and sex life, any entries in or removals from criminal records or records on minor offences that are kept on the basis of the law. It is worth noting that Law no. 03/L-172 on the Protection of Personal Data, which was abolished by Law no. 06/L-082 on the Protection of Personal Data, required that **sensitive personal data be specifically protected and classified** in order to prevent unauthorized access and use of them by third parties, except cases provided for by law. Given the above, it is clear that there were no legal obstacles for health authorities to protect the data of citizens infected with HIV and AIDS, but such an action was not encountered during the Ex officio investigation of this case. on the Activity, Structure and Functions of Health Services for HIV-AIDS
63. Administrative Instruction (Health) No. 02/2011 on the Activity, Structure and Functions of Health Services for HIV-AIDS, which derives from the Law No. 02/L-109 on Prevention and Fighting of Infectious Diseases, aims to regulate the organization, administration, structure and operation of health services, which are provided by health institutions for the prevention and control of HIV/AIDS in Kosovo, stipulating that the Ministry of Health should establish the **Kosovo**

**Committee for HIV/AIDS.** Also, the Administrative Instruction expressively defines the rights of persons living with HIV/AIDS, stipulating that such persons will receive care, support and treatment services in accordance with best international practices and their HIV/AIDS infection will be held confidential. Regarding the test results for HIV-positive persons, the Administrative Instruction stipulates that the blood test results may be only communicated to the tested person, spouse, cohabiter, parent or legal custodian if he/she is a minor or has lost the ability to act. The Instruction also specifies the situation when an HIV/AIDS infected person is in education-correctional institutions, residential social care, prisons or detention centres and, in the case of an HIV positive results, the test result is communicated to the staff who are tasked to handle counselling and information, and to the staff who is taking care of and is treating the infected person in the education-correctional institutions, residential social care, prisons or detention centres. During the reporting period, on 24<sup>th</sup> of April 2019, the Minister signed the Administrative Instruction no. 1/2019, which shall enter into force one week after the date of signature and shall supersede Administrative Instruction no. 2/2011 on the Activity, Structure and Functions of Health Services for HIV-AIDS.

64. Administrative Instruction (MoH) No. 08/2015 on Clinical Guidelines and Protocols, which derive from Law no. 04/L-125 on Health, aims to establish organizational structure, to define tasks, composition of administrative bodies, time limits for drafting, revision and revocation of Clinical Guidelines and Clinical Protocols in the territory of the Republic of Kosovo, in order to improve quality and safety of health services. But from the legal analysis of this case, there are many deficiencies with regard to regulating standard operating procedures.

### **Findings of the Ombudsperson**

65. Based on the findings presented and the facts gathered, as well as the analysis of relevant laws that determine the right of persons infected with HIV and AIDS in Kosovo, the Ombudsperson has **ascertained violations of fundamental rights and freedoms**, as the relevant authorities failed to comply with the constitutional and legal obligations in regard to persons infected with HIV and AIDS and, as a consequence of the situation created by the malfunction of CD4 and Viral load measuring apparatus, reagent supplies and lack of ARV medicines for children, there was direct implications in treatment of these persons.

66. The Ombudsperson concludes that it is positive that Kosovo continues to have a low number of persons infected with HIV and AIDS, however the discrimination and stigma surrounding key populations, the lack of continuous ARV therapy for treatment of persons who live with HIV and AIDS, especially for children, not included in the list of essential medicine, constitutes a violation of the rights of these persons. The situation may be more sever considering the statements by authorities that some of the citizens are receiving HIV and AIDS services in neighbouring countries, such as Northern Macedonia and Albania. Based on

findings from meetings with responsible people in the institutions , it was reported of a dysfunctional linkage between public and private health systems, failure to report HIV-tested cases in private health care institutions, as well as failure to report to NIPHK. Kosovo has a solid constitutional framework for protection of persons with HIV/AIDS; a relevant number of laws and policies, including the National HIV/AIDS Strategic Plan for 2018-2022 in Kosovo, which is a continuation of previous national HIV/AIDS plans and is based on Global Funds HIV Grants and the recommendations given by the WHO mission, involved in 2014, to review the previous strategic plan and HIV program; in the findings and recommendations of the study on Transition Readiness Assessment, completed in 2017.

67. The Ombudsperson concludes that Kosovo has a strong constitutional framework for the protection of people with HIV and AIDS, as well as numerous relevant laws and policies. In this regard, some major achievements have been made. However, progress has not been equal to a number of challenges that hinder proper implementation. These relate to the health system in general, including low budget contributions to health, poor implementation of laws and policies, poor coordination among sectors and among authorities, poor monitoring, poor accountability and participation of key populations, including marginalized groups, in developing HIV/AIDS-related policies in Kosovo. During investigations, it was found that professionals respect privacy and confidentiality, but was also found evidence of forcing patients to take HIV/AIDS tests prior to surgical interventions, and such actions go unpunished, which violate human rights to privacy and serve as a deterrent for seeking services from public health professionals in Kosovo.
68. In previous reports, the Ombudsperson has raised the need for inclusion of sexual education in schools and several actions have been undertaken in this regard. However, we consider that more efforts should be put for comprehensive sexual education of children, adolescents, and youngsters out of school.<sup>38</sup>
69. The Ombudsperson asserts that, despite the legal infrastructure on the treatment of HIV/AIDS in Kosovo, health authorities have, at least until now, failed to develop clear standard operating protocols for handling and managing HIV cases in health institutions. The Ombudsperson also raises the concern about blood tests performed in blood transfusion facilities. Despite the belief that there are strict controls and testing before blood is administered to the patients, the information obtained from the field and the cases investigated earlier by the OI, whereby violations were found and reports with recommendations were issued, show indications of possible negligence while performing blood tests in blood

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<sup>38</sup> Ombudsperson Institution, Sexual and Reproductive Health and Rights in Kosovo: A Reality Beyond the Law, December 2016, accessible on: <https://www.oik-rks.org/2016/12/08/raporti-te-drejtat-ne-shendetin-seksual-dhe-riprodhues-ne-kosove-nje-realitet-pertej-ligjit/>.

transfusion facilities, as there is no external control mechanism for the quality of blood and its products.

70. As regards the failure of the Director of the Infectious Diseases Clinic to cooperate with OI, during the investigation of this case (see paragraph 4 of this Report), the Ombudsperson recalls that Article 132, paragraph 3 of the Constitution stipulates: “*Every organ, institution or other authority exercising legitimate power of the Republic of Kosovo is bound to respond to the requests of the Ombudsperson and shall submit all requested documentation and information in conformity with the law*”; whereas Article 18, paragraph 6 of the Law No. 05/L-019 on Ombudsperson stipulates: “*The Ombudsperson has access to files and documents of each authority of the Republic of Kosovo, including medical files of the people deprived from liberty, in accordance with the law and can review them regarding the cases under its review and according this Law, may require any authority of the Republic of Kosovo and their staff to cooperate with the Ombudsperson, providing relevant information, including full or partial file copy and documents upon request of the Ombudsperson*”; whereas Article 25, paragraph 2 stipulates: “*Refusal to cooperate with the Ombudsperson by a civil officer, a functionary or public authority is a reason that the Ombudsperson requires from the competent body initiation of administrative proceedings, including disciplinary measures, up to dismiss from work or from civil service*”; while paragraph 3 of this Article stipulates: “*In case when the institution refuses to cooperate or interferes in the investigation process, the Ombudsperson shall have the right to require from the competent prosecution office to initiate the legal procedure, on obstruction of performance of official duty.*”

Based on what was said above and pursuant to Article 135, paragraph 3 of the Constitution of the Republic of Kosovo: “*The Ombudsperson has the power to make recommendations and propose actions when violations of human rights and freedoms by the public administration and other state authorities are observed*”. In accordance with Article 18, paragraph 1.2 of Law No. 05/L-019 on Ombudsperson, the Ombudsperson: “*(...) is responsible to draw attention to cases when the institutions violate human rights and to make recommendation to stop such cases (...)*”; as well as: “*to recommend (...) promulgation or amendment of administrative and sub-legal acts by the institutions of the Republic of Kosovo.*” (Article 18, paragraph 1.7)

Hence, the Ombudsperson

## **RECOMMENDS**

1. To the Ministry of Health:

- *In accordance with legal authorizations and competences, allocate special budget lines from the overall MoH budget for funding/dealing with HIV/AIDS cases in Kosovo.*
- *Through competent bodies, supervise the application of Guidelines for*

***Voluntary Counselling and Testing.***

- *Draft guidelines/protocol on treatment and management of HIV cases, with standard operating procedures.*
- *Undertake all necessary measures regarding the supply of antiretroviral therapy for all ages.*
- *Undertake all necessary actions to ensure that the CD4 measurement and Viral Load testing equipment at NIPH are functional at all times so that cases of non-functioning of equipment are not repeated in the future.*

2. to the Health Inspectorate:

- *In accordance with legal authorizations and competences, inspect the issue of patients' obligation for compulsory laboratory treatment on HIV, HBsAg and HCV testing prior to undergoing elective operations in surgical clinics, caesarean operations in gynaecological clinics, as well as in other public and private health institutions.*
- *Address the lack of antiretroviral drugs for children at the Infectious Diseases Clinic in Prishtina.*
- *In cooperation with other responsible authorities, to notify the private health institutions conducting HIV testing, on their obligation to report HIV-positive cases to the NIPHK, in accordance with the Law.*

3. To the Hospital and University Clinical Service of Kosovo:

- *Issue a written decision and inform all subordinate units that it is their duty and obligation to cooperate with the Ombudsperson and provide all required information, including the full or partial file of the case, pursuant to the Constitution of the Republic of Kosovo and Law no. 05/L-019 on the Ombudsperson.*
- *In accordance with the legal competences and authorizations, take all necessary measures and ensure the presence of a clinical psychologist in the Department of Infectious Diseases Clinic in Prishtina*
- *In cooperation with subordinate units, take the necessary measures that Room no. 2 of the Ward A at the Infectious Clinic in Pristina be provided with the necessary inventory and a monitor for patient vital signs (Spo2, Pulse, TA, Temp, Ekg) for treatment of persons with HIVAIDS.*

Pursuant to Article 132, paragraph 3, of the Constitution of the Republic of Kosovo ("Every organ, institution or other authority exercising legitimate power of the Republic of Kosovo is bound to respond to the requests of the Ombudsperson and shall submit all requested documentation and information in conformity with the law ") and Article 28 of the Law No. 05 / l-019 on the Ombudsperson ("Authorities to which the Ombudsperson has addressed recommendation, request or proposal for undertaking concrete actions, including

*disciplinary measures, must respond within thirty (30) days. The answer should contain written reasoning regarding actions undertaken about the issue in question."), we kindly ask you to inform us about the actions taken regarding the issue in question.*

Best regards,

Hilmi Jashari  
Ombudsperson