

# THE REPORT ON THE HUMAN RIGHTS OF LGBTI+ PERSONS LIVING WITH HIV



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LGBTI+ PERSONS LIVING WITH HIV

**Prepared by:** Defne Güzel, Kerem Dikmen (Analysis of Legislation)

**Editors:** Murat Köylü, Defne Güzel

**Translation:** Özge Gökpinar



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Ceket Medya

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## 1. Foreword

In June 2020, we have initiated the monitoring and reporting study on human rights violations against LGBTI+ persons living with HIV (lesbian, gay, bisexual, transgender, intersex or bodily, gender and sexually diverse persons). I can easily state that this study herein, which we have finalized by combining the extensive interviews with analysis study, has fulfilled its aim of identifying the human rights violations and the fields where those violations took place against LGBTI+ persons living with HIV; in order to focus on this in detail while providing a ground where LGBTI+ persons living with HIV can provide their direct testimonies regarding their lives.

Within the scope of the study, we had the opportunity to conduct in-depth interviews with 10 LGBTI+ persons living with HIV. Despite the fact that we could not come face to face with these persons due to the pandemic period and met them online, I am delighted with this study; since Covid-19 could not upend our ties while the interviews caused a spontaneous overflow of common and powerful feelings. I would like to thank all the participants I had the opportunity to meet, who did not refuse me in sharing their stories openly. It was an excellent experience for all of us that this study and report took place via online interviews in the days when the Covid-19 pandemic taught many of us the experience of working remotely at home. Although there were technical problems such as interruption of internet connection, seeing that online interviews still preserve the authenticity of the stories, albeit on screen, made this work productive.

While conducting interviews with LGBTI+ persons living with HIV, unfortunately, we could not get the chance to meet and access diverse identities and experiences. For this reason, I would like to highlight the reasons behind this situation as follows in order to avoid any deficiencies in the report:

Lesbians and bisexual women living with HIV are exposed to discrimination, especially by their families, partners and healthcare staff who are

aware of their HIV status. Unfortunately, women cannot disclose their HIV status, given the extent of discrimination and violence they may face. The heterosexist, cissexist patriarchy interrupts women in every field, just as they prevent women from developing policies and a discourse in this field.

The safety of sex workers living with HIV is under threat, especially by their clients. Sex workers living with HIV are constantly afraid of being disclosed. When these people are infected with HIV, they either have to leave their jobs or they are forced to disclose themselves. Therefore, they cannot share their HIV status due to economic concerns.

Transgender persons living with HIV are subjected to discrimination by healthcare staff in their medical procedures. The healthcare staff is refraining from providing HIV+ transgender persons with medical procedures or transgender persons are exposed to a series of discrimination and violence during these processes or the exorbitant prices are charged to them by healthcare institutions.

LGBTI+ prisoners living with HIV are exposed to discrimination and violence by the prison administration and officers. They are isolated, cannot access their medicines, and cannot enjoy the necessary medical checks and treatment.

LGBTI+ persons with disabilities living with HIV face various problems in accessing health; due to non-inclusive hospitals and physical conditions.

LGBTI+ foreign nationals living with HIV are unable to access medicines, especially due to recent regulations on health insurance and they cannot receive appropriate treatment due to uncertainties and they cannot reach the information on the alternative options due to language barriers.

LGBTI+ elders living with HIV cannot stay in nursing homes in line with the regulation and they are forced into loneliness and isolation, even when they cannot meet their basic needs.

As it is known, the process of living with HIV has changed a lot. With routine checks performed every three or six months while using one

or two antiretroviral pills (ART) taken once a day, those living with HIV can live as healthy as anyone else. ARTs destroy viral copies by blocking HIV from reproducing and return the immune system back to an almost normal state by diminishing the number of HIV RNA in a milliliter of blood to 20 copies, while also eliminating HIV transmission by reducing the concentration of virus in the blood. Thanks to this situation, which is referred in the literature as “Undetectable=Untransmittable (U=U)”, HIV+ persons who achieve and maintain an undetectable viral load (the amount of HIV RNA in the blood) by taking antiretroviral therapy as prescribed cannot sexually transmit the virus to others

However, HIV phobia has not changed unfortunately. Prejudices against those living with HIV persist. While HIV was a health crisis in the 80s, today it is a social crisis for those living with HIV. Those living with HIV cannot come out, they are dismissed from their workplaces, are targeted, exposed, isolated, forced into ghettos. HIV-related stigma manifests itself differently exposing those living with HIV to violence, suicide, and death.

In this qualitative report, you will read the problems, requests, needs and stories of LGBTI+ people living with HIV as well as how their rights are violated. During this study, we heard from the participants frequently that “It was also very good for me to review my own story and evaluate whence I came”. This means a lot. Despite all the pressure and persecution, persons living with HIV drag themselves up by their own bootstraps. HIV+ persons are coming out of the closet, they organize, grow together, become stronger, claim equality. They initiate a movement in which they embellish the literature by adding their own stories while centering of the subjects in it.

Finally, I would like to express my profound gratitude to my colleagues Umut Güner, Yıldız Tar, Murat Köylü, Metin Uzun and Kerem Dikmen who offered their cooperation and understanding throughout this study.

I hope you enjoy reading this report

Defne Güzel

## 2. Introduction

### 2.1. The Significance of the Research

According to the data of Ministry of Health as of 31 December 2019, there are 24.237 persons who were diagnosed with HIV in Turkey. Taking into account the possible number of persons who have not been diagnosed, it is estimated that the total number of persons living with HIV is doubled and around 50.000 in Turkey.

Persons living with HIV have been struggling with various human rights issues from the past to the present. Persons living with HIV are primarily discriminated against in all fields of life due to prejudices and incomplete information. They are exposed to violence, cannot access health-care services, and cannot gain the necessary economic income for a quality of life. The empowerment practices, sources of motivation, self-care needs, and psychological well-being of those living with HIV are ignored. In case of where persons living with HIV are cis-heterosexual women, LGBTI+ persons, persons with disabilities, foreign nationals/immigrants, children, sex workers or prisoners, they face double stigma and marginalization, the dimension of discrimination and violence become even profoundly ingrained.

In Turkey, HIV and LGBTI+ movement are combatting against to say stop to this discrimination and violence, in order for ensuring equal rights for persons living with HIV. While persons living with HIV become apparent worldwide in the 80s, the first non-governmental organizations working in the field of HIV were established in Turkey. These NGOs, which are mostly contain doctors "fighting against AIDS", have focused on recognizing the virus and on specializing in the field of diagnosis and treatment. However, in 2000s, these NGOs were replaced by NGOs established by persons living with HIV instead of doctors, which we can call "positive organizations". These positive NGOs have been working

on solving the problems of persons living with HIV since the beginning of the 2000s.

The fact that HIV policies are developed in line with healthcare since the 80s has made the experiences and requests of those living with HIV invisible unfortunately. It is a well known fact that persons living with HIV today want to get out of the ghettos by breaking the chain of discrimination and violence, want to benefit from equal rights like the others, want to continue their daily lives without being exposed to discrimination/violence, and want HIV policies to be transformed into such policies centring persons living with HIV. These requests are also in line with the human rights claims of LGBTI+ persons and their organizations. Therefore, our research was designed to provide an in-depth inside for HIV and LGBTI+ persons' intersectionality.

It should be recalled that HIV was even referred before as GRID, or Gay-Related Immune Deficiency, when first recognized cases of AIDS were restricted to gay men, especially in USA in the 80s. Gays have been referred as criminals of HIV by conservative politicians and religious authorities. While HIV (Human Immunodeficiency Virus) is an issue that concerns all people without distinction, as its name suggests, it is still attributed to LGBTI+ persons from past to present and is used as means of intimidation or suppression. Extremist rightwing politicians and religious authorities voicing these unscientific beliefs, incompatible with reality fed by the ideology of hatred, still target LGBTI+ persons. This study we have conducted is important in terms of enlightening the experiences of LGBTI+ persons living with HIV in this grip of dual oppression.

Considering these reasons, it is essential to include monitoring reports on the violations of rights against persons living with HIV, just like LGBTI+ persons. NGOs have been working on this issue from the past to the present and they report the violations of rights faced by persons living with HIV. However, besides these reports on violations of the rights, the studies in which people living with HIV can share their experiences, problems and claims are more rare.

This study, which we started in June 2020, has emerged in order to fill this gap. While persons living with HIV are trying to come out of the

closet, organize, grow together, become stronger, claim equality, show the uniqueness of their stories to the society, it is important to carry out activities that will create this opportunity. This study showed us the experiences, needs and problems of LGBTI+ persons living with HIV, and it has served as a fundamental resource for what steps we can take in the future for overcoming these problems.

Meeting with 10 LGBTI+ persons living with HIV, providing a space where they can tell their own stories, enabling them to revise their own success stories, and most importantly, to have a mutual learning process in this field, constitute another significant element of the study.

The expectation from this study you will read is to contribute to human rights literature that focuses on the subject and reflect the experiences of intersectional discrimination and enlighten the empowerment stories of persons. Our aim is to carry out more studies in the field of SOGIESC<sup>1</sup> and HIV, to create a platform where persons living with HIV can come out and speak up just like LGBTI+ persons do, to update rights-based language/literature and to ensure that discrimination, hate and violence to come to an end immediately.

## 2.2. Methodology and Content

The first step of the research was to review and analyze the international and national literature. Priority was given to international publications specifically on HIV and LGBTI+, especially the intersectionality in-between. These publications are preferably research reports of the bodies of the United Nations and the European Union. Although they are not reflected exactly, the content of these resources were inspired for the research questions. Particularly in this research, categorizations of problem areas of these resources were benefitted and the question patterns. Research questions were identified at the team meeting held after this preliminary study. While identifying these questions, the focus was on human rights issues regarding HIV and LGBTI+ persons in Turkey. The method of “face-to-face semi-structured interview” was adopted to ensure the study was based on the subjects’ qualitative ex-

<sup>1</sup> SOGIESC: Sexual orientation, gender identity/expression, sex characteristics/intersex status

perience while reflecting their uniqueness. It was decided that the question patterns and the attitude to be followed by the researcher would allow people to express their positive thoughts and experiences in an empowering way. Due to the Covid-19 measures, the interviews were conducted online with the research participants via online tools, rather than being face-to-face interviews. In this regard, the participants were selected among the persons the research team knows, who were open about their HIV status or SOGIESC.

## 2.3. Sampling

Participant	Gender Identity	Sexual Orientation	Level of Education Completed	Age	Period of time after HIV diagnosis
1	Male	Gay	Bachelor's Degree	30	5 years
2	Male	Gay	Bachelor's Degree	25	4 years
3	Not specified	Not specified	Bachelor's Degree	22	2 years
4	Non-Binary	Pansexual	Master's Degree	25	5-6 years
5	Male	Gay	High School Graduate	41	16 years
6	Trans Woman	Straight	Bachelor's Degree	39	6 years
7	Male	Gay	Bachelor's Degree	25	5 years
8	Female	Bisexual	Bachelor's Degree	27	2 years
9	Agender	Gay	Bachelor's Degree	25	2 years
10	Non-Binary	Bisexual	Bachelor's Degree	24	3 years

## 2.4. Ethical Principles

The protection of privacy and “protection of the participants’ personal data” was one of the most important ethical principles followed in the research process. The researcher’s personal information was not shared by the researcher with team members or third parties without the data was anonymized and coded. The names of the participants or their relatives were never made visible in the research report. The information

that could form an opinion about the participants' identity was not reflected in the report. The purpose of the research and the field of use of the report as the final product, were explained to the participants in detail.

Another ethical principle adopted by the research team was the "inclusiveness" of the research. Although a small number of people were open about their HIV status and SOGIESC, it was tried to ensure the sampling to be as pluralistic as possible. However, it should be kept in mind that the sampling included mostly "university graduates"; in terms of education level and mostly in their "20s" in terms of age, in terms of the universe of the report. It should also be emphasized that the sampling is mostly composed of people who have a certain level of relationship with civil society, based on the principle of inclusion.

Finally, according to the "reliability" principle, no additions were made by the researcher while reporting the participant's statements. Their testimonies were reported completely. The researcher refrained from making comments that exceeded the statements of the participants. During the interviews, it aimed to ensure the participants share whatever opinions and experiences they wanted to share with their free will in their own specific way; participants were not motivated or manipulated to get the specific results that the researcher would like to obtain.

### 3. Key findings and recommendations

#### 3.1. Key findings

- a. There are not enough channels where LGBTI+ persons living with HIV can tell their stories anonymously or openly. During the interviews, the participants often expressed their positive feelings as they had the opportunity to review their experiences, to tell their own stories, and for their stories to serve a purpose.
- b. Participants stated that they would not be able to take legal action in case of violations of rights they were subjected to or might be subjected to. This could negatively affect their careers or could not apply judicial procedures due to the danger of being victimized.
- c. Regarding potential discrimination, it has been observed that in some cases, participants do not consider the violations of the rights as a violation of their rights or give up their practices due to the risk of a violation of rights. As an example, we can provide the statement of a participant who gave up enrolling in swimming pool because the test is required.
- d. The participants have expressed different opinions on LGBTI+ organizations and HIV organizations. Most of the participants do not find the studies of LGBTI+ organizations, HIV organizations, other NGOs and the counseling capacity of these organizations sufficient on HIV.
- e. It has been reported that healthcare professionals often cause violations of the rights of LGBTI+ persons living with HIV in accessing health. Based on the statements of the participants within the scope of the study, LGBTI+ persons living with HIV are very likely to be exposed to LGBTI+ phobia and HIV phobia in healthcare centers.

- f.** It is also prominent in the statements of the participants that they face issues led by healthcare staff in hospital processes regarding their medical issues other than HIV on account of their HIV status.
- g.** Participants mostly stated that they do not trust the authorities and institutions. They express their negative opinions about the Diyanet's sermon provided on 24 April 2020 related to those living with HIV, and they stated that such sermons make them feel bad and make their lives even more difficult.
- h.** The inadequacy of HIV-related school and university curricula was frequently emphasized. Participants reminded that up-to-date information on HIV should be disseminated among the society and relevant professionals. They stated that the HIV issue should be included in the curriculum the, the awareness on HIV of society and especially the healthcare staff should be raised and that more academic studies should be conducted in the field of HIV.
- i.** It is observed that those living with HIV are frequently exposed to discrimination in their social lives by their families, partners, friends or colleagues.
- j.** When the participants were asked what they think about HIV, they stated that they have embraced their HIV status, they were conscious about it, they did not remember that they were living with HIV most of the time until they face discrimination by the society while reminding them their HIV status.

### **3.2. Recommendations**

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- a.** During the development of the legislation and public policies that concern LGBTI+ persons living with HIV, appropriate conditions for their participation should be created to share their experiences and requests.
- b.** The principle of equality and non-discrimination contained in the Constitution, Turkish Penal Code, Law on Human Rights and Equality Institution of Turkey and the Labor Law should cover clearly the sexual orientation, gender identity, sex characteristics and health status

as the protected characteristics. Legislation, institutional capacity and policies regarding hate crimes should be developed in line with the recommendations and standards of rights-based organizations and the Organization for Security and Co-operation in Europe.

- c. LGBTI+ persons living with HIV should be empowered to take legal action against the violations of their rights. In that regard, necessary procedural and institutional arrangements should be made in order to minimize the disclosure or other violations of rights during the judicial procedures.
- d. Rights-based psychosocial supports should be integrated into public policies so that LGBTI+ persons living with HIV can continue their life without restricting themselves due to the risk of discrimination. In that regard, LGBTI+ persons living with HIV should be empowered, especially in the field of employment.
- e. LGBTI+ organizations, HIV organizations and other NGOs should build their own capacities in order to provide appropriate counseling and guidance to LGBTI+ persons living with HIV.
- f. Considering that the right to health is one of the most fundamental rights, discrimination against LGBTI+ persons living with HIV should be completely prevented.
- g. HIV-positive persons should not be restricted from access to health-care because of their illnesses other than HIV, on the pretext of their HIV status, and their applications to the healthcare system should be welcomed without subjecting them to any discriminatory treatment.
- h. Existing institutions and authorities should strengthen themselves in the field of HIV and human rights, and should not provoke the society by using HIV as a tool of hate speech. In order to guarantee and promote the human rights of LGBTI+ persons living with HIV, institutions and authorities should develop legislation and policies.
- i. Education and curriculum should be updated in the field of HIV. HIV should be included in the curriculum and the number of studies conducted on the rights of persons living with HIV should be increased.

- j.** LGBTI+ persons living with HIV should be empowered against the discrimination they face via social services provided by the public and civil society.
- k.** Academic and cultural studies should be conducted in order to ensure the history of HIV and LGBTI+ movement to be covered by the social memory with the help of up-to-date information and a rights-based discourse.
- l.** Prejudices against HIV should be eliminated, persons living with HIV should not be exposed to the violations of rights, the literature on HIV should be updated, and policies focusing on persons living with HIV should be implemented urgently.

## 4. Level of Knowledge on HIV before diagnosis

HIV, Human Immunodeficiency Virus, is a pathogen that works by using host cells for making new copies of itself by infecting cells of the human immune system called CD4, which play a central role in responding to infections in the body. HIV kills CD4 cells by altering the structure of the cell and copies itself. The drugs used in HIV treatment today are used for restricting the spread of HIV to CD4 cells of the immune system. Current medications are greatly effective in this regard. Persons living with HIV keep HIV under control by using daily one or more drugs and can live as healthy as anyone else. Thanks to “Undetectable=Untransmittable (U=U)”, situation as it is called in the literature, by taking antiretroviral therapy as prescribed, the immune system returns back to an almost normal state since the number of HIV RNA is diminished to 20 copies, while also eliminating transmission characteristics of HIV by reducing the concentration of virus in the blood.

In this case, the persons do not reach the stage of AIDS, Acquired Immune Deficiency Syndrome, the most advanced stage of HIV that is reached without the effective treatment. In addition, HIV infection is eliminated with the appropriate use of pre- and post-exposure prophylaxis, which we know as PReP and PeP. HIV drugs are provided free of charge to persons covered by the insurance of SGK (Social Security Institution); as well as to persons covered by GSS (general health insurance) by paying their monthly premiums and to green card holders in Turkey.

In the 80s, it was possible to talk about a “crisis” environment as there was no medicine yet and many persons lost their lives due to AIDS-related causes. HIV and persons living with HIV were reflected as gruesome and macabre by the media and public perception in USA in the 80s and this was splashed across headlines in Turkey for days during 90s. HIV took its place in the media and society as a means of intimidation. Despite current developments, this perception still continues. HIV is still mentioned as an infection attributed to LGBTI+ persons, sex

workers and foreign nationals. HIV is attributed to the non-white ones, those afflicted are guilty of immoral acts.

Due to insufficient information on sexually transmitted infections, the public cannot update their knowledge on HIV. This situation mostly affects those living with HIV. Those living with HIV cannot be open, they are isolated, exposed to violence and cannot access healthcare services due to the lack of their knowledge or lack of the knowledge of the society. Even though LGBTI+ persons and sex workers, who can be described as "key groups", have a greater sense of the HIV issue than other segments of the society, they face many problems during the diagnosis process due to non-qualified and non-inclusive healthcare services. There are various "positive" NGOs and other NGOs centering HIV issues in their studies to provide solutions to such problems Turkey

Participants we made interview with within the scope of the study provided the following answers to our question regarding their level of knowledge on HIV before diagnosis:

**KAA:** *"I can begin with evaluating the extent of my knowledge on HIV in the past. As an activist in LGBTI+ movement and HIV, I know HIV, but I thought it was just about distributing condoms to LGBTI+ persons. While doing this, I did not really have the awareness of using condoms. I learned that I was living with HIV while I was an LGBTI+ activist. That was when I found out that I did not actually take part in HIV activism, I thought that I knew HIV. Actually, there was a completely different world there. There was a completely different realm and I was just talking through my hat. Millions of information I do not know is there and that scares me. When I first found out, I was not upset and did not break down. I just challenged myself and enveloped myself in this for months. I cannot say that I welcomed this and I was not afraid as an activist, rather I got scared, worried. In fact, my doctor who informed me about my status told me that: "What did you do to yourself? Those words rang in my ears constantly. I started questioning myself. I was already in LGBTI+ activism by questioning over and over. It was the same with HIV. That is how I learned that I was living with HIV in 2015".*

Since the stories of persons living with HIV are not provided sufficiently and there is little chance to hear the experiences of social subjects, those living with HIV may experience confusion during the process

when they are diagnosed with HIV. Because, unfortunately, the details and feelings to be expressed by the subjects are not sufficiently included in HIV studies.

**İAO:** "Actually, I first learn about HIV through a friend of mine living with HIV. I learned the process via my friend. Then I learned about it for the second time with my own experiences. I met someone before I found out I was living with HIV, and I thought maybe we might have a relationship, so I should undergo a test. My result was positive after the test. Then the process started for me. I had awareness on HIV. I knew that you are not necessarily dying because of it. There were just too many issues on my mind related to labor life and these were troublesome."

**AAA:** "There is a LGBTI+ association in the country where I was born and growing up. They also work on HIV. I was learning about HIV due to them. We were also taken to the trainings about AIDS by school. But these trainings were just exhorting that "do not use drugs or you will die of AIDS". I just remember these. When I came to Turkey I was not able to have regular health checks. I had to go to my country to have it done. I started getting sick for a while. My lymph nodes and my feet became swollen. I had no insurance. I could not go to the doctor and I was applying lotion on the body, drinking sage. I was trying to ensure my healing like this."

Alternative practices regarding HIV are not solutions. HIV drugs i.e. antiretrovirals, are drugs that have been approved as a result of long-term tests, neutralize the HIV RNAs in the body and allow the immune system cells to reproduce. For this reason, no alternative options should be used in place of HIV drugs.

**İEY:** "Years ago, I had flu unlike all the flus I had in the past. Night sweats, high fever... I slept for four days. But I had no information about HIV at that time. Somehow it passed. I recovered at the end of a week. A quiet period has begun. My energy has returned. One year later, a friend of mine directed me to a survey study as part of a surveillance project. I also participated. They asked questions on safe sex. They never said they would give me a gift at the end of the meeting."

**İDİ:** "I was a child then. When my father was reading the newspaper in the eighties, he could not read the word AIDS. He used to say "Ajda". He

*would describe it as a dangerous epidemic. This is a memory from my childhood. I had no information that HIV is a sexually transmitted infection. I also did not know that it affected USA drastically. Nor did I know it was common in queers. When I found out that I was living with HIV, I realized that I was even myself phobic. No matter how much you know, you do not understand what the other person means if you are not the subject. I have never met a HIV-positive person in my life, I was the first myself. Then, as I came out to a few persons, persons also did the same around me. Recently, HIV activism has grown stronger. That is why you were exposed to phobia on social media last year. Ten years ago, nobody was talking about HIV on social media."*

HIV activism has been getting stronger in recent years. Although this activism has predominantly focused on healthcare studies since the nineties, persons living with HIV have been organizing, coming out and building discourses about their rights.

**İKH:** "First of all, I heard about HIV through LGBTI+ activism. I was indifferent before and I did not have such awareness. When we look at LGBTI+ organizations in comparison to the other rights-based organizations, they raise the issue of HIV more. My concerns arose by it. If it is on the agenda that much, it means there is something in us. I also learned about the right information those times and I prepared myself to get a diagnosis."

**İAE:** "Although I am always in feminist, queer, anarchist environments, HIV has always been an issue that I ignore. I am very angry with myself about this. I was frequently encountered with it but I always ignored it, until I was diagnosed. HIV was always in somewhere, but I had never been there somehow. When I was diagnosed I was thinking, how am I so ignorant? Actually, I was trying to be directed to this subject somehow. HIV was an issue that suddenly hit me although my denial."

**İÇB:** "Me and HIV have known each other for a long time. I learned that a friend of mine was HIV-positive and I was very sad, very concerned about my friend. I researched what HIV is without showing my concerns. I could not ask anyone. I thought it was hurtful to ask this. I knew that it could be suppressed by using a drug. I was familiar with the concepts. I had no great fear."

**IDE:** “*I do not remember how I heard about or learned about it. I joined the movement at a young age, so I think I know it as a political issue.*”

Knowledge on HIV may not be up-to-date before being diagnosed with HIV. For this reason, it is very possible to get confused during diagnosis. For this reason, it is important to receive support and counseling from non-governmental organizations working on this issue after diagnosed with HIV. Examples of the lack of knowledge and prejudices on HIV demonstrate that society's knowledge on HIV needs to be strengthened and updated. Knowledge on HIV prior to diagnosis is very necessary for the persons to know their process when they learn that they are persons living with HIV, to break prejudices, to be aware of their rights and to claim their rights, to organize, to cooperate and to advance their process easily.

## 5. Become acquainted with the epidemiology of HIV infection

### 5.1. Test Process

Today, HIV diagnosis is determined by blood tests performed in private hospitals, private laboratories, state hospitals and anonymous test centers. The first positive test is called "false HIV positive test" followed by the "confirmatory test". Although blood tests such as p24 and PCR are used in the first test phase, the ELISA test is frequently used. Western Blot blood test is frequently used as the confirmatory test. In particular, the Western Blot test has a longer waiting time than other tests and is not performed in every city, in every hospital. Due to prejudices about HIV and the lack of updated information, getting tested, waiting for a test result and getting a diagnosis can be challenging for persons.

Within the scope of the study, the participants stated the following about the testing process:

**IAO:** *"After the test I started to wait and after two weeks they did not provide any notification in that regard. In my previous test experiences, the news was provided earlier. After two weeks, I called the place where I was tested. They guided me to a lab. I asked them if there was any trouble. They said some of my tests were positive so I had to come there. On the phone I asked insistently "Is it HIV?" and they said "yes".*

Diagnostic information should not be given to individuals, even to themselves, via telephone, e-mail, due to the privacy of the patient. Although the legislation is regulated to tell persons about information face to face, mistakes such as notifying persons on the phone and mailing documents to their home address are frequently encountered.

**KEK:** *"I did not go to the hospital. I just thought of starting the treatment. For a few months, I was introverted. I suffered from depression.*

I tried to communicate with my close friends, but when I did not get a positive response, I stopped communicating with them. I could not accept this situation. With the help of a friend of mine living with HIV, following the discussions and supports of my friend, I realized that I had to go now and I went and got tested at the hospital. It turned out positive as I expected. The waiting process was not tense for me. Because before that my mind already accepted it; I went to the hospital without no doubts I knew that I was already HIV positive. I had the information thanks to a LGBTI+ organization before, I was acting unconsciously at that time, though".

**I<sub>EY</sub>:** "They gave me a card from a lab that I can be tested for free. I also told my friends. They got this card too and we went there together with our test cards. Three days after the test, they called me and said "we have to take more blood since the former sample was not enough". I called other friends to see if they were called as well in that regard. Then a friend of mine who will receive the test result said "Let me come with you". We went back to the lab together. The officer there did not give us much information. They said "we cannot evaluate this result". They referred us to an associate professor at another hospital. "I was tested here. Why do I have to go to that hospital?" I asked. They said "our kits are not adequate"; I sensed something wrong. I thought that there was something wrong but they did not tell me. You are thinking much at that moment. I went out and said my friend "Nothing. The tests kit here are ruined."

**I<sub>DI</sub>:** "I learned by getting sick. I had surgery before I found out I was infected. They do routine blood tests during that surgery; back then I was negative. I said, "Oh, I have learned the results". At that time, there were no free test centers either. I was not using protection always. I got very ill at work and went to the family physician. The drugs the doctor prescribed did not help. I could not even swallow the pills. I had a constant feeling of vomiting. The doctor told my sister to take me a good hospital. We went to the hospital's emergency service. I guess the doctors were suspicious since the female doctor there told me to come to the infection clinic on Monday. I got tested there, three days passed. They called from the hospital again. I went there with my sister and they wanted me to meet with the lab officer. Then I understood. As soon as I entered the room, I asked if I am HIV positive. After I got the affirmative answer, the whole world crashing in chaos about my ears. I still feel the trauma of that moment. It

*was the darkest day of my life. The doctor was trying to persuade me by saying that they need to confirm the result, it could be false positive. But I knew the result potentially because I was not protected. Then they sent me to infection clinic. Meanwhile, I was getting well".*

Healthcare staff should receive training on providing information and guidance. Information and guidance should be provided by using an appropriate and professional approach.

**IAE:** *"When I was diagnosed, I got over it in a short time, but I suppressed it. I am not sure about my stance regarding that matter. It was kinda new process for me. I was diagnosed during a standard checkup, I applied for a smear test. They detected a problem. They recommended a biopsy not about HIV, but about something like a cyst. I did not know exactly what happened because the doctors were too vague. Some tests were applied as these were required for the biopsy. I went to see the anesthesiologist who would tell me if I was suitable for a biopsy. By reviewing the papers in front, the anesthesiologist waited ducking the head and asked for some more tests due to some unusual results. I was told that one type of hepatitis was positive. When I asked, I was told that it was HIV. What I remember about that moment is not how I was diagnosed with HIV, but the doctor's facial expression and way of saying it. I guess that it was what they call secondary trauma. More than the diagnosis itself, the way I was informed bothered me. I did not react at all. I said okay. Then I walked a lot. I could not think of anything. I did not get on the bus. I started to walk and started crying halfway through. I bought alcohol, cigarettes and chocolate and went to my house. The confirmatory result took about fifty days. Staying in limbo was difficult. I thought it was okay. I was fully accepting for a moment, then I thought it might be negative. I was always in a dilemma. I spent those fifty days at home. When I found out that I was positive, it was very comforting because my path became clear."*

Due to the lack of information, persons may experience tension and trauma during the waiting period. For this reason, medical systems should be developed to provide diagnostic information to individuals quickly. The fact that persons are able to or not able to prepare themselves to be HIV-positive during the waiting period, and the fact that the confirmatory test is negative after the self preparation process can be traumatizing and psychologically devastating for the persons.

**iÇB:** "I went to the hospital for my routine checks. Two weeks later I got my test result and that is how I learned that I live with HIV. Each time I was tested, I was thinking that I can be positive. Since I knew I can get such a result, I was not surprised and continued my treatment by learning. No matter how conscious I was, I was not aware of its social dimension. I thought it was a medical problem and everyone saw it that way. The processes I went through later showed that this was not the case"

**İDE:** "When I got tested I learned that I am living with HIV. Before the test, the acute period was very painful for me. I slept in the hospital and HIV did not come to mind. After I left the hospital, I was tested at an anonymous test center. I went to get the result. My test results were not among the negatives. My results were checked among others for about 15 minutes, then 15 more minutes passed while they tried to find my results. After a calming speech, my result was provided. After a few teardrops, I informed to my close friends immediately. I have informed everyone."

**AAA:** "A friend of mine found a discounted test opportunity from a private clinic. I went there I was tested and got the diagnosis there. I waited four days. I never thought that I was positive, but I thought there should be a reason behind why I got so sick. I was ninety percent sure that I am not HIV positive. I got tested in a private lab. They were so sweet. I was thinking at that time if I am positive, I would kill myself."

Knowledge on HIV before the diagnosis is vital. Persons can access updated information on their own and equip themselves with this information before the diagnosis, and this may lead them to have a relaxed diagnosis process. For persons who cannot access the information on HIV, this may not be the case.

**İKH:** "I found out the result in my first test. I was tested in the health complex of the university while I was still at the university. In the previous year, I had an active sex life and I was always worried about living with HIV. At some point I went there with a friend of mine and I learned my status. It was strange that the result was positive at my first test. Actually, it was not strange, since I was not infected with HIV while just sitting at home. That was the moment I met with HIV. The first doctor I contacted was not bad. I think I have not been informed well. The doctor said we have to wait a little longer for my test results when my friend

*obtained the negative result. The doctor did not inform me about what we were waiting for. Then I was sent back to another hospital. After getting a second positive result from there, I was asked the same questions we all know. Although I have experienced gay relationships, I wanted to mark myself as straight and the doctor marked it as such since the doctor was also my family physician.*

**KAA:** “*I was on a vacation and I was very tired during the holiday. When I decided to go back from vacation and go to the hospital, I first went to hematology. They said there was a blood problem probably. Doctors could not figure it out. Since I also was taking part in HIV activism, I wondered if I should have the ELISA test. After ELISA test, the result was positive. The process started there for me. When the doctors could not figure out what is wrong, I smelled the rat. I was feeling something is not right in my body. For example, I was suffering from nocturnal fever, but I knew these were wrong. I had never woken up due to night sweats. I was telling myself that I am HIV-positive during the 15-day waiting period after I got suspicious and went to get tested with a friend.*”

Due to the wrong perception created on HIV, this process, which can be called the “process of facing with HIV” where the persons are waiting for their test results, is tense for many persons. Many questions such as “What am I going to do now?”, “I wonder if I am really HIV-positive?”, “What if I am not HIV-positive?”, “If I am HIV-positive, for how long do I live?” come to the mind. Most of the time, learning positive status can be better than the feeling of being in limbo.

## 5.2. The attitude of healthcare staff during the diagnosis

During the diagnosis process, it is important for the doctor to share the test result with the person diagnosed in a constructive language by providing correct information and guidance. As a requirement of the right to privacy, the information of the persons should not be shared with third parties and the status of the person should be told during the face-to-face meeting. Healthcare staff can often traumatize persons living with HIV during the diagnosis process due to their lack of knowledge and prejudices regarding HIV.

The statements of the participants about the attitude of the healthcare staff at the time of diagnosis are provided below:

**KA**: “When the doctor told me “What have you done to yourself? Your results are positive”, I did not feel a new shock. I was expecting such result and I was thinking how to live with it. I can be suppressed in any area, but I was saying my health is my freedom and I thought that HIV influenced my only freedom at that time. That is why I had the feeling that I was not healthy for the first time. I was very worried at first and my doctors did not suggest me. They treated me mechanically throughout the process. But on the other hand, they acted as if it was something normal. They were not thinking about my psychological state. I am a very quiet patient anyway.”

**IA**: “The doctor was nervous while giving me the news. He was saying dramatically and I was trying to be more comfortable. When I said that I was protected and paid attention to my protection in most of my relationships, the doctor said “You do not pay enough attention my dear”. But I feel very good with my current doctor.”

The patient-doctor relation requires a specific and professional communication. It should not be the case for doctors to criticize or frighten their patients. This kind of behavior is against medical ethics.

**AA**: “When I went back to get my results, they said “we have to talk to you. Hepatitis was negative but HIV was positive. I immediately started crying. I left the lab without listening to the rest. Then my boyfriend saw me. He was already working in that clinic. He said “let's talk to the doctor and he put me back inside”. The doctor told me that this situation is not dangerous and he was wishing me to get well soon. I said “are you kidding, how will I be well?”. It was a tense process. They suggested that I should be tested with confirmatory test. Since I was a foreigner, I constantly faced obstacles and those were the times when I was poor. Even when I went to the hospital just to find out the money needed for the tests, I could not learn the amounts. I learned these eventually and I was tested and the result was confirmed. Then they had me meet with an expert. The doctor ordered me to stay away when I entered to the room. When I asked if I can be deported, the doctor said that “you probably were infected in your country of origin. You can be deported”. I had to go to give blood. I went downstairs to give blood. The assistant

doctor said "Oh how young you are. Drugs may not work, you know?". I gave my blood and left. I was thinking in the garden of the hospital about how long I will live. Since everybody says so, I thought I was going to die at the age of nineteen."

**IYE:** "At that time, I was working in Call Center and trying to schedule my time. Finally, I found time and went to the hospital. Of course, I was thinking that I had AIDS on the other hand. I think I experienced my biggest trauma there. Then I did not have major traumas, I quickly accepted it. I did not hide it from my close friends after that time. I went and got a barcode from the hospital. I went to the infection clinic to see the doctor there since I was guided from the lab. I was going to meet with the doctor they recommended from the lab; I showed the doctor the lab document. The doctor stood up suddenly and opened the windows and washed hands. I was ordered not to get closer to the table. I said I would like to meet with the doctor recommended for me from the lab, however that person was not there at that time and this person took the sample. I insisted to see that doctor, they ignored me. I was told to give my blood and then come back. "Why are you acting like this? I am just waiting for an answer", I said. I was then ordered to give me the blood and come back. Then the man responsible for the blood tests asked for my barcode. He told me" since you came from infection unit, you have to provide your number". I resisted. "You have to report this otherwise I do not get your barcode" he said. I left halfway through the process and sat in the garden. Then I stood up and went home. I made a research on the internet. I filled my head with a lot of unnecessary information. (...) Later, I tried to get an appointment from the person I could not meet in the hospital who was recommended for me by the lab staff. I got the appointment and went to see the doctor. Of course, 15-20 days had passed by the way. The doctor told me "you are a young person. In the samples we examined we obtained stable test result that you have the virus". My ears were burning. I've struggled with too many thoughts running through my mind. When I left the doctor's room, what was on my mind was the thought that now I have AIDS. I thought nobody should know about this. I decided that now I have to change my life, that no one should find out that I died for this reason."

**KEK:** "The hospital process was not bad as I expected. I was lucky and I came across a good doctor. The doctor's approach and communication were very good, I got informed as well. I do not know if the doctor should

*have this kind of approach but we communicated well. There were just too many tests, three in total, for confirmation. I was constantly tested for two months. I started using medication two months after I obtained my first results."*

Unfortunately, LGBTI+ persons living with HIV can be exposed to LG-BTI+ phobic attitudes even if they are not exposed to HIV phobic attitudes of healthcare staff. Those who are diagnosed face problems in accessing healthcare due to a healthcare service that are not qualified and inclusive.

Although it is an ordinary procedure for healthcare staff to report a diagnosis of HIV to the person, this is not always the case for persons who learn about living with HIV. Persons who have no knowledge on HIV may not remember or listen to the guidance provided after learning about their status. For this reason, healthcare staff should ensure that persons are calm and can listen to them during informing persons about their status while providing updated information.

**IDi:** "The HIV RNA count was 8.5 million. CD4 count was 144. The doctor told me "sometimes those are peak in some persons when they are newly infected. Even if you were not treated, it would fall after a certain time. This stage is actually the AIDS stage. They should have brought you in a wheelchair with these counts. Do not get upset." And took me to the back room and continued talking "Look, I have been an infection specialist in this hospital for 11 years. There are 300 files in this room and each one is HIV positive. 15-20 of them do not come because they refuse treatment, I do not know their results. Among the rest, we have so far lost one person, who died as a result of a heart attack due to old age. Now you can have a normal life, even have children, do not worry." I was open to my doctor as a transgender and I am satisfied with the approach. I even invited him to be a spokesperson for an event, but the doctor could not come because it conflicts with the doctor's other plans".

**IKH:** "The doctor at the university was very good, though. The doctor told me no one dies because of this, comfortably; by simplifying the process by saying that I should use one medicine a day. This felt very good. The reaction of the doctor was well. The doctor sent me to a polyclinic. For three years, a doctor there has dealt with my process. It has gone well."

**iCB:** “The doctor who will follow my process has informed me well by saying that I need psychological support. At that time, the doctor advised hospitalization without requesting a separate appointment for each procedure. You are not lying down at the times anyway. You are there during the day for the tests. They were taking my blood there and the assistant doctor was reading an article about HIV. I got a little nervous. In general, I did not face any major problems in the hospital. But it was annoying that to be kept in isolated rooms.”

There are positive examples as well as negative examples regarding the communication of healthcare staff during the diagnosis process. It is clearly seen in the statements of the participants that the doctors have empowered the patients during these positive examples.

### 5.3. Psychosocial status and support

HIV is perceived as something terrible by society, with the influence of the media's provocative statements. Since the 80s, it has been used to reinforce LGBTI+ phobic and racist discourses by the discourses such as “gay cancer” “Russian plague”, “transvestite disease”. HIV has been used as a means of intimidation among societies and has been demonized, so to speak. It has been attributed to the non-pure, the non-white and marginalized persons. With the effect of these reasons, updated knowledge on HIV could not be widespread and the problems and claims of persons living with HIV were ignored although there are developments regarding HIV. Given the perception that the process is still happening as in the 80s, the psychosocial status of those living with HIV can be tumult during the diagnosis process. For this reason, free and inclusive psychosocial support mechanisms should be recommended by healthcare staff during the diagnosis process and necessary guidance should be provided.

Statements of the participants regarding their psychosocial status are as follows:

**KAA:** “Then I had to take medicine, but I had no insurance. I could not figure out what HIV was yet and I was in a state of depression. That is why I did not take care of the procedures on insurance for 3 months and

*did not take any medication. I refused to use it. I questioned whether I wanted to continue this life. I had a problem with an HIV organization at that time and realized that I had to prepare for a tough struggle”*

**KEK:** “They gave me two drugs. Four tablets from one, one tablet from the other daily; these were prescribed medicines to be taken on a full stomach, morning and evening, separately. Now I was living focused on taking medicine. It constantly reminded me that I was living with HIV. The reason I had breakfast or eat something was to consume these medicines. I had to give up sleeping late in the evening. It was all for ensuring a more organized life. This constantly reminded me that I was living with HIV. Then I attended a meeting held by a HIV association. We exchanged ideas with the friends working there. They told me that the drugs I used not recommended anymore and that I should talk to my doctor. I talked to my doctor. The delegation convened. They took my opinion on what drug it should be. They asked why I wanted to replace a drug that was going well. I told them that I did not want this to affect my life. They changed my medicines and now I take one medicine a day.”

The approach of HIV organizations in the diagnostic process of subjects plays a critical role. These communications should be carried out professionally and make the subjects feel empowered, rather than being compelled.

**IYEY:** “The company I worked for was going to open a branch in another city and I talked to them to go to that city. I told them that since my mother is ill; this city would be better for us. They negotiated with HR and approved my request. I changed my phone number and bought a new SIM card. I told my mom that I was appointed to another city. At that time, I was sending depressive mails to an HIV-positive mailing group I was in. They were trying to sooth me but I was telling them “You are deceiving yourself”. I was talking to one of our friends from there. I asked their help. With this help, I rented an affordable house in the city I went to. I spent the first six months by going between office and home. There were only walls and my job. I was thinking of neither HIV nor the future. Later, a friend of mine whom I loved very much could not reach me, reached my mother, got the phone number from her and called the company and somehow was able to reached me. We talked on the phone and my friend asked “What are you trying to do?”. I said “Let’s talk after work, not now”. I called later and it was the first time that I told someone

*that I am HIV-positive. I said "I do not want anyone else to know about it. My friend told me that there could be a remedy and that I should not be silly, then came to the city I was in. We hugged and cried. Of course my friend thought that I was going to die and this period should not be spent alone without enjoying every minute. My friend told me "you should return back to your mother. Your support system and your friends are there". I thought about that too. Why I worried about what they will think of me after I die, I will die anyway. So I will not feel anything. Then, I spoke with my team leader. I said "I wanted to go back to my old town. My mother could not do it here. It is difficult to get to the hospital". They did not accept my request. They said "we do not want to lose you, but it is impossible". Then, I resigned. Despite my debts, it was an incredible relief. I was thinking "Well, I will die anyway". I evacuated the house. I returned back and told my mother that they closed the branch in that city, that is why they sent me back. I went to the hospital again. I reminded the doctor myself and said that I could not listen to what was told me at that time."*

Being diagnosed with HIV can be compelling for persons regarding their current circumstances and conditions. Not knowing the stages of the process for HIV-positive persons who seek the first support at the doctor after their diagnosis, often causes the feeling of unrest in the process. For this reason, it is of great importance that doctors provide advice regarding expert and peer counseling.

In most of the interviews, the participants stated that the more they learn about HIV the more the process facilitated and peer counseling reinforced this facilitation. This once again underlines the importance of psychosocial support mechanisms.

## 6. Response by the healthcare and social security system

### 6.1. Attitude of healthcare staff

Although the infection and microbiology departments have relatively more information about HIV, other healthcare branches may not have updated information on HIV. One of the main reasons for this situation is that the sexually transmitted infections is not covered in an inclusive and adequate level in the curriculum of graduate and undergraduate programs. There are more than 25 thousand persons living with HIV in Turkey. It is thought that there are more persons who were not diagnosed yet. Considering the number of persons diagnosed in central hospitals, healthcare staff in local healthcare institutions may not be aware of the routine health checks of a person living with HIV. This situation negatively affects the attitude of healthcare staff against persons living with HIV.

Participants shared the following experiences on the attitudes of healthcare staff:

**KAA:** “In the hospital I am going to, blood is taken in the common area. The nurse once asked me why I gave so much blood. I told them I am HIV positive. During next three-months in the medical checks, the nurse told me that the blood samples was no longer taken there, I was forwarded to the microbiology. I think something like this probably happened there: I was giving the blood there for many years and when they learned from me, I guess they started a discussion and they did not want to get the blood samples of those living with HIV. That is why I think I had to go to microbiology department.”

**İAO:** “When I told the officer there when I first entered the hospital that I wanted to talk to the doctor, the officer asked my name and surname and said “Is this you?”. I did not even know this person. This person was

*not my doctor, just an officer who worked there and learned my status via my ID information. Also in my former hospital, when I warned the nurse to wear gloves; the nurse replied "Why should I wear it, for you or for me? and I replied "for the sake of both of us".*

**KEK:** *"I had an argument with the nurses, especially with a nurse. When I warned the nurse for using gloves during blood sample, the nurse asked me "Why are you giving blood? Do you have hepatitis?" I said, "No, it is for the ELISA test. Then the nurse asked, "Is there anything?" This time I said, "I do not know if I am positive or not, it is you who should use gloves, why do you ask?". Then the nurse started to grumble. This annoyed me. In addition, the secretaries I applied before entering the doctors' room can speak loudly that I live with HIV during and after the process of the prescription given by the doctor. This situation bothers me. They are not conscious enough."*

**AAA:** *"Nurses are mean. When I wanted to give blood for my other tests like for hepatitis, they said "we examined your blood six months ago; we cannot do now". When I say "I have an active sex life" they say "You should settle down". I walked into a nurse's room for my blood to be taken and I was just joking about my tests for HIV by saying that how soon I will die or will I die? The nurse told me "well, of course". After I learned that I am positive, I wondered if I was really going to die."*

**IYEY:** *"In that hospital I just went to, I sweat the small stuff. The officer was wearing gloves while giving my blood tube to the lab and taking my blood, but not wearing the gloves during the other blood samples. I felt the power to say "this is the discrimination you are doing right now, you should wear it for everyone all the times. The woman was understanding and said, "we did not think that way". Then I told the doctor about this and the doctor told me that I was right and have a conversation with them. The other time I went, the same woman was taking the tubes from everyone with her gloves. I smiled and thanked. In hospitals, there used to be an understanding that those persons are different and extra measures should be taken; as if it could be infected in social life. That was the approach against HIV back then. In those years, the number of HIV follow-ups was few. They saw few patients. The more examples they see, the more hospitals have to improve themselves. In the year I was diagnosed, 256 persons were diagnosed. Last year, 4000 persons were diagnosed. In this situation, the officers see more patients living with*

HIV. Compared to the past, such behaviors are rare now. The more HIV+ patients the institution take care, the more action they develop.”

It is possible to say that a person's right to privacy and protection of personal data is systematically violated in practice. As a matter of fact, those living with HIV perform many practices such as meeting with their doctor, prescribing medication and giving blood during their routine controls. At many stages of the system, the privacy of those living with HIV can be violated. In addition, in accordance with “universal protection guidelines” healthcare staff should take the same sterilization precautions not only for HIV but for many other diseases. No extra medical protection measures are required for HIV.

**IDI:** *“I always tried to be open to healthcare staff. I also told my family physician directly. The doctor tried to protect me by calling the nurses when I was with them while giving blood. For example, the doctor warned them to be careful against hepatitis without exposing my HIV status. I had a problem with the liver and during abdominal ultrasound I shared my status with the doctor directly but the doctor's approach was biased thinking that I am suffering due to an advance stage. I think the phobia is less in big cities. Last year I faced phobia for the first time. I got another STI. I was not scared. The doctor gave me three penicillin after the test and asked my to obtain those from the pharmacy and approach the emergency service for the injection. I had to wait fifty minutes after the procedure, in order to ensure the penicillin does not cause an anaphylactic shock. Two dosages were injected but when the third comes I was on the holiday. I have a colleague with me that do not know about me. I asked my colleague to take me to the nearest hospital and wait in the car, I will have an injection. I persuaded him without telling him what kind of injection it was. When I went there since it says HIV positive on my prescription, the nurses were in panic. They did not touch me, they tell each other about my status, humming around about there is someone with AIDS. Then I pulled down my pants to be ready for the injection. The nurses used the intern child next to them for the injection. I stood up with cotton in my ass. They told me not to leave because the process was not over since the penicillin froze. They changed the needle with a thicker one. My buttocks bruised. While leaving, I told them that they are phobic and due to their fear they let an inexperienced person to use the needle. The nurses told that they are teaching the interns. I told this to my doctor. And my doctor told me “you are right. In large hospi-*

*tals, the doctors and nurses are used to these because the population is large; they necessarily deal with HIV-positive persons. They are scared in small cities, we have to educate them."*

The majority of the participants complained that the nurses did not have sufficient knowledge about HIV and took unnecessary sterilization measures. HIV is a health condition that should be known completely by all healthcare staff and attention should be paid to those living with HIV.

**İKH:** "I have had problems with the healthcare staff. When I sit down to give blood, naturally I do not have to disclose my status. The staff look the label over the tubes stating HIV RNA. After seeing the label, they ask "Why are you giving blood?" ... When I say that I am HIV positive, they say "You have to tell us for us to take action accordingly." If your fear is HIV, you need to accept all your patients as HIV positive and act accordingly. I had arguments with two or three persons like this".

**İAE:** "In the emergency, the doctor asked me, "How were you infected sexually?". I was in such a position where I could never defend my rights. While taking blood once, the nurse asked, "Why are you giving so much blood? I said I do not know. Then the nurse told me "do not you know your diagnosis?" When I shared my status, they scolded me according to them I should have informed them in order for them to wear extra gloves.

**İÇB:** "When you are diagnosed, they ask questions. I directly said I had a relation with a man. Although they pretend to be comfortable, they somehow make you feel unwanted there. They give the message that they are talking to me just to do their job."

LGBTI+ phobia that persons living with HIV may suffer during hospital processes negatively affects the treatment. LGBTI+ persons living with HIV can be traumatized by healthcare staff and the other patients due to non-inclusive healthcare institutions, they are unable to keep up with their treatment practices and sometimes they stop treatment halfway through.

**İDE:** "By the way, I see very few persons. There is no counter in the hospital. I see two persons, including the doctor. I felt anxious due to a few of the nurses. One of them had good intentions. But behind all these

*positive attitudes; I think the reason is that I am comfortable of going there. If I was someone who asks a lot of questions and is anxious, their attitudes can change. I do not have any dialogue with anyone. When I did not say I am HIV-positive during a therapy, they gave me water with a glass cup, but after that with a paper cup. This is something I have experienced."*

Due to lack of information and prejudices, healthcare staff can make the healthcare processes of persons living with HIV difficult rather than facilitating them. Many persons living with HIV report in the interviews that nurses bullied them during the bloodletting phase, while secretaries revealed their HIV status knowingly or unknowingly. The warnings of those living with HIV to the nurses to wear gloves for the sake of both parties, regardless of HIV status draws attention.

## 6.2. Treatment Process

Those living with HIV go to the hospital for routine checks within the periods of 3 or 6-months after the tests and examinations, even though they undergo some tests and examinations during the diagnosis. In the meantime, medication is prescribed in 3 or 6 boxes in proportion to the dates of routine checks. It is expected that the "treatment process" will continue in this way as long as no other situation occurs.

During the interviews, the participants shared the following experiences regarding their treatment practices:

**KAQ:** *"I did not have to report to Public Health after the diagnosis. The research hospital providing diagnosis did this for me. I now go for routine checks every three months. I am going there with pleasure. Sometimes I forget that I am living with HIV. I am taking three drugs in a day. I feel anxious when I forget. When I thought that I cannot apply to associations to get information from there, I found a closed group on social media. It was a solidarity group. They even sent me medicine for a period. Persons there were very worried about the drug. So seeing the seriousness of the process scared me. In time I realized that I should not be afraid. I try to get the pills on time, but this has evolved over time. It happened when I did not take medication for a week. I saw that nothing was activated, I realized that these fears were unfounded. By the way, I*

*was taking five drugs a day at first. I was taking two in the morning and three in the evening. Now I use one drug in a day. When I was taking five drugs I thought it was exhausting me and I thought my bowels were irritated. I guess it was a side effect of these five drugs. I got rid of it after changing the medication."*

Although those living with HIV can still use combined drugs, the drug treatment period is mostly reduced to one drug per day. HIV drugs, the ARTs, are the most ideal drugs to suppress the HIV. It is recommended that the drugs be taken every day at the prescribed time. Otherwise, there is a possibility that HIV in the body may be resistant to the drug and the drug dose may be increased.

**IAO:** *"Anxiously I went to the hospital. The doctor there explained the process to me and sent me to infection department. The doctor at the infection checked my RNA count and prescribed medication. We were waiting for the result of the confirmatory test at that time. When I got a different result, they reconfirmed, but in the meantime, I also started the medication. My notifications were also handled by the same hospital. Now I am using Genvoya. I go for the routine check every three months and I am very happy with my hospital. I do not see any worries in the faces of the healthcare staff. They always wear their gloves and I have encountered any HIV phobic attitude. But due to the pandemic process, I have been buying my drugs directly from the pharmacy for a while before I go to the hospital!"*

**KEK:** *"The only problem in my hospital process is that I cannot get an appointment. I have to start trying to get an appointment one month before I run out of medicine. I try to cope with the processes such as getting an appointment and getting a test result before I run out of medicine. Fortunately, I meet with understanding doctors who prescribe me medication without my test result, they try to solve my problems."*

**AAA:** *"At first I was using drugs containing ephedrine. That is why I was dizzy. Now I am using Genvoya, it is better. I cannot be examined in Turkey. I have been away for a few months already. I had no insurance and could not go to another doctor. I went to another doctor by brazen it out; I begged the assistant, crying I told that I have no money, I just want to see the doctor; Somehow I entered the doctor's room, the doctor relaxed me. When I asked how long I can live; "What are you talking*

*about? You will not die" the doctor said. The doctor could not do the examinations, just trying to look at my blood results. Numune Hospital did not load my blood results into the system, and I also had a problem there. Almost a year passed. I collected money and went to my country. I had my tests done there. They said you do not need to start medicine yet. I did not use then. It has only been a few years since I started taking medicine. Until September of this year, I was always going to my country for medication and control. The hospital there is terrible. Nobody cares about you. There is no online system. You go to the archive room and find your document, go to your doctor and wait in queue. You are tested, your medication are prescribed and you leave."*

Foreign nationals living with HIV in Turkey may have difficulties in accessing the drug and treatment in their home countries. Therefore, inclusive HIV policies should be applied in every country that lacks services in that regard.

**I<sub>EY</sub>:** "I was told that my The Western Blot result was positive. I was told I would use four drugs a day, and in case of side effects, there would be two more for me. I asked if I take those drugs every day and I was told that as long as I use these, HIV will not be able to harm me, I was informed about some of the side effects as well. I thought that my life would pass me by consuming those drugs. I went to the doctor at that hospital. This doctor was nice, very calm and understanding. The doctor told me "You are hearing this for the first time now and you may be thinking of something else when I am talking. So whenever you want, you can ask about the things on your mind", he was so thoughtful. "I must be in heaven" I thought. We talked for forty minutes. The doctor said "I am talking with you to obtain right knowledge". If there were no association, if I had not been there, I would have undergone an unnecessary toxoplasma treatment. In this loneliness, I liked to have someone who guided me for free. At first, I was going to my routine checks with boredom, but after my contact with the association, the more I learned about my rights, the stronger it became, the more comfortable the process became."

**I<sub>DI</sub>:** "I started with the Kaletra and Truvada duo, and at the end of the first month, my HIV RNA count, which was 8.5 million, had dropped to about 8.500 after using a package. My CD4 count increased to 350s. These drugs are a real miracle as the doctor said. Kaletra was giving me

a headache. My cholesterol was not decreasing. Kaletra was changed first with Tacay. They switched to Hivent instead of Truvada. They do my routine checks regularly. They even warned me when I missed it. Unfortunately, I had not been able to go there since and before the pandemic. It has been 9-10 months. I will go there again in a week."

**İKH:** "My first process was a little suffocating. After all, they always send you to different places for examinations. Verem Savaş is on the other side of the city, for example. I cannot understand why the departments are being distributed. I also feel like not everyone is informed in the same way. For example, they do not do the same examination to my friend. They say that it is necessary for one phase of treatment. But why is not the case for other patients? It was very confusing. I became aware of the vaccinations a year after. Nobody told me. Maybe it was not supposed to have a standard, but there is no standard. They do not know each other. They do not know what procedures I underwent. I see this when I change the hospital. Maybe yes, it should not be like this for privacy but still they should know and follow my process. Even when I come across another doctor in the same hospital, even they do not know about each other. I feel like there is no system where they write notes.

I was sent to an out-of-town hospital for confirmation. I went there and gave blood there. I think it is because Western Blot is not done everywhere. I started the treatment before the confirmatory result. When I went out of town to give blood, my process was again easy as I had acquaintances there. But I also felt there that it was this personal relationship that protected me. The system is not used to you and persons like you. You can only use your personal relations if you can. It is about being in the right place. I still see curious eyes, but it is not so difficult anymore. The doctor's room has always been a bit safer for me, but the hospital process is always a bit more difficult apart from that. If you live in a small place, everyone goes to the same polyclinic. You know everybody more or less.

Once I enter the doctor's room, there were ten interns behind the doctor. The doctor asked me questions, but I know one of those interns. They came to observe. I could not do anything. I was shocked and I wrote down on my phone that there is someone I know here right now; I would like to come later; then after the doctor saw it I left the hospital. So I am already studying at that university; the person studying medicine there is someone I know and it is not taken into account. You are not in-

*formed about this process. Consent is not taken. You meet them directly. Although it is a doctor, there are ethical codes, after all, your relations there are binary. In general, I came across knowledgeable smart doctors, but I always prevented them from showing me too much interest. They can tell me how much alcohol or cigarettes I can use. But this is coming out of a place like you're lacking. These are harmful to everyone. The way the doctor gave me such advice made me uncomfortable. One of them said that "You are clean, you should know about the cases we see" while looking at my test results. I am trying to stop this conversation. I may not feel strong enough to talk about this. They actually do this to honor you, but; I want to say that mind your own business. It is annoying because I can come next month with more infections, this oppresses me. This should not affect their service, there should not be a good patient and the bad patient. Will my failure to follow your advice affect the standard of your treatment?*

*I started before my confirmatory test result came. Then I always set a standard for myself. Once I changed my medicine. Regarding the Stribild I normally use, another doctor gave me Genvoya by saying that there is no more of this drug. Why does not the other doctor know about this? Despite the side effects, the ministry pays for it, pharmacies sell it and I use it, which means the drug is still on the market. I give six tubes of blood every six months. I have been looking negative for a long time."*

**IAE:** *"It is fine now. I am comfortable now. Even in this pandemic period, I was always comfortable. As my first doctor was stalling me, so I went to another hospital to start the medication,. They recommended that person to me. The doctor explained everything one by one and took care of me very well. That is why I got through my illness process quickly. I still visit the same doctor."*

As studies on HIV treatment continue, drugs are also improving. Combined drugs are gradually being replaced by a single drug to be used per day and these drugs are developing day by day and their side effects are minimized. Lack of information, prejudice and disclosure for HIV surveillance in small cities is relatively higher than the large cities. However, the same difficulty may be the case in large cities. For this reason, those living with HIV have the opportunity to continue their processes in less trouble-free places after changing a few doctors by gaining experience with advice.

**IDE:** “The doctor there sent me to the hospital. I got an appointment from the hospital. They just did research until that time. Frankly, I did not have a few of the general tests and examinations done. I underwent a genotypic resistance test and did not get the result until recently. I was nervous about the processes I went through with my partner. I had to buy and get a few things done from a few places. I am very afraid of basements. I am also afraid of overly protective clothing. I accidentally went below the ground floor and I am afraid of the elevators. A man in an astronaut suit came before me and I collapsed. I began to cry. The man was shocked and the door closed, and I went up to the top floor where I should have gone at first. I did not have much trouble in the contact with other units. Either they did not know what was happening or they knew well. I did not have a doctor of my own. I always went to the same doctor during my frequent visits. Then, on my second visit, the doctor told me “Are you bisexual? At least do not infect it to the women”. There was no one I can call my doctor. Whichever doctor I come across, current information is displayed on their screen. I am also a bit prejudiced against male doctors. I feel better with women doctors. I started taking the medication on 2 December. I attended in training; it was just then. Being in a crowded environment just when I started my medication made it easier for me to come out”.

The most prominent matter about treatment practices in the interviews is the following: Although those living with HIV have problems in their first test and examination processes and with their first doctors, they determine their doctors over time and continue their processes more peacefully or they want to continue. During routine checks, which are simplified with three or six-month checks and medication prescription, those living with HIV are asking for doctors who are knowledgeable about the issue, who cannot distract themselves, and who will especially follow the drug changes and arrange and facilitate their medication.

### 6.3. Experiences regarding medical issues other than HIV

HIV is categorized under the status of chronic diseases by the World Health Organization (WHO). While routine sterilization is performed for every patient care process, there is no need for extra sterilization for HIV. HIV drugs only interact with limited drugs. A person living with

HIV does not need to undergo an extra procedure due to a medical issue other than HIV. Considering that persons may not know their HIV status; the same sterilization procedures should be applied to all patients. HIV dies within a few seconds, when exposed to air. In addition, it should be remembered that the transmission characteristics of HIV in persons who receive treatment are eliminated.

When we asked the participants about their experiences with health issues other than HIV, they shared the following experiences:

**KAA:** *"In the beginning of the process, I had a tooth pulled in unauthorized clinic for fear of being exposed to the doctors, then I cried for how I did this to me. Once I went to the cardiothoracic surgeon to quit smoking. When I was asked if I have a chronic disease, I said I am HIV positive. The doctor asked me what this was and he told me that I should pay close attention to myself, since a basketball player had racked with pain until his death. I told him that this was no longer the case. It was just a pity that a thoracic surgeon was so ignorant in that regard. Once I told the doctor who check if I have a fever that I am HIV positive. I may have fever due to this. The doctor shouted, "How can you not tell me that? I said that I mentioned the medicines I use on the form and I reminded the doctor to check the form and to be careful accordingly. Then I filed a complaint against the doctor because the door was open and persons were looking at us. It was a violation of the rights of the patients."*

**KEK:** *"While I was using the medication for acne, I stopped using it when I was on HIV treatment. Then when my counts were normal, I went to the doctor and they did a routine blood test. Before they prescribe medicine by saying that the values are normal, I told them that I am HIV+. Then, the doctor told that they could not prescribe the drug at that time. I was informed that they need to get approval from my doctor and they sent me. I told the doctor "you were going to prescribe it if there has been someone that you do not know if they are HIV positive. So, it has no effect, the doctor repeated that they should get the approval. I did not go back or did not get the approval. I live with my pimples, I am happy."*

Although HIV does not interfere with any other treatment process, in the case of using another drug, HIV drugs, the ARTs, may interact with other drugs. This situation should be followed up by the experts by ap-

propriate checks. In addition, if it is determined that the person is living with HIV before any surgical intervention, in terms of the medical safety of the person living with HIV, appropriate protection methods should be implemented in accordance with appropriate protocols.

**AAA:** “I recently went to the doctor for my teeth. I explained my status there. I was going to have root canal treatment. They told me “the next time you come, bring a document about your HIV status”. I said that they could not ask for such a document. I asked to see the doctor and when the doctor came, we had an argument. The doctor told me that since the students will come to examine, they asked such a document for their health. They apologized when I rebuked more. Three days later I got an appointment again. While I was waiting in the queue, I saw that it was written “HIV risk” near my name. Then when I walked in, the room was covered with aluminum foil. The doctor was already wearing protective clothing for Covid. The expert was there for me, not a student. After the process was finished, a special team came and took everything.”

**IYI:** “The doctor sent me to the doctor again who traumatized me, since this doctor will manage my controls. I went there with disgust. The doctor told me “we have another problem, your toxoplasma is positive. It is a virus that passes through unwashed fruit and vegetables that can affect the brain. It will be difficult to find medicine, you can get UTC drugs”. I discussed this with the association. They also sent my results to a doctor. The doctor told that even though my toxoplasmosis is positive since my CD4s are over 500, it is not in a position to replace my CD4s and that my situation should be monitored. Of course I calmed down, but I lost confidence in the hospital. They stressed me out about the unreal facts. Then the association recommended another hospital for me.”

**IKH:** “I was having dental problems for a while. I went to a private hospital, spending a lot of money. They made me to fill out a form. It was written “AIDS” on the form. I am not in the AIDS stage by the way but I marked it anyway. I gave it to the secretary and wait in the queue. Then, I entered the doctor’s room. The doctor asked similar questions. I said that I filled out in the form that I am HIV positive. Before I could finish my sentence, the secretary entered the room in panic. As if something has happened. The doctor’s approach was very calm and thanked me for sharing my HIV status. I needed a canal treatment. The doctor told that they need information in written format from my doctor for this

*procedure. I could not get treatment that day, I got a signed letter first and went there again. I also told my own doctor. My doctor informed me that it is normal procedure up to now, but every question they ask me from now on is not about my process and can be as a result of phobia. This explanation sounded good, but whatever happens, I just wanted to get rid of my tooth problem. The doctors have to protect me right here. When I suffer from swellings and pain in my mouth, this should not happen. I do not know what would have happened if my medical problem was more serious. Would they ask for document then? That is the problem. If the progress for someone who is not HIV positive is fast; it should be the same for me. For example, I have nasal polyps. I am aware of this for a long time, but after diagnosed with HIV, I do not know about if HIV status will affect the surgery. I consider it as a dispensable issue since it is not a vital problem.”*

**İAE:** “The tests were very exhausting for me. My first doctor was exhausting me. They were not working with the appointment system by the way. I had to find them, reach them. The doctor was constantly forgetting things; was distracting me. After three months I was able to start the medication. My CD4 was 154. It was 350 initially. The doctor was an extravagant, indifferent person. I already had an extra biopsy process. While these tests were going on, I underwent the biopsy. I waited for hours in a place like a matinee. I waited naked for about four hours. The operating room was like a fridge. My CD4s were low. HIV-positive persons were taken the operating room lastly. I waited for the other surgeries to finish. I fainted in the end during vascular access procedure. After I got out of there, I had diarrhea, became ill, I was at home for 15 days for recovery.”

**İÇB:** “I had an appendicitis surgery. I went to the hospital in the morning. My appendix ruptured and they immediately prepared for the surgery. Before that they asked me if I have a chronic disease. I had to tell them about my status but by thinking what they were doing to the patients, I did not tell them, because it is not a must for me to tell them, they do not have to know it. Then, I had the operation. I was still under general anesthesia; the doctor and nurse entered the room. The doctor poked my arm to wake me up and told me “why did not you tell us that you are HIV positive?” I replied “why should I tell?”. The doctor tried to disturb my conscience and said “Do you know how many doctors and patients are entering that operating room. How can you take such a

*responsibility? We would have taken sanitation measures in line with that? And I said, "Are you performing surgery without taking measures? Do you imply that?" "Let's put it in a nutshell" the doctor said while leaving the room. When I went for my stitches, the female doctor in the emergency room, while four patients were waiting inside, suggested me to tell the doctors that I am HIV positive from now on. I criticized her a bit at that time. If you do that, they do not want to mess with you and they avoid argument. But if you cannot answer, they try to oppress you. According to them, you are defective therefore you have to inform them. You are guilty and sinful. They expect you to be embarrassed for not informing them.*

**IDE:** *"When I went to private clinic for my teeth, I also started medicine. They charged me an exorbitant price. They expected me to pay such a high price three times more than one of my relatives paid for the same procedure a month ago. My relative paid less. It happened because I wrote on the form that I am HIV positive. They already asked me questions about HIV. There were times when they could not decide who will deal with me, they wore two gloves, they wore a corona suit."*

Due to other health problems of persons living with HIV, healthcare staff may unnecessarily request reports or documents. This can lead to the disclosure of HIV status, stigmatization and discrimination as well as delay in healthcare procedures. The importance of the universality of the right to access to health emerges precisely in such cases. The process of going to the hospital where persons are followed up and getting a report and sending the report to the doctor dealing with the other diseases causes delays in access to healthcare compared to others. When persons try to overcome these barriers themselves, they may encounter reactions. As stated before, it is sufficient to follow "universal protection guidelines" in case of HIV like in many other diseases. The transmission routes of HIV are specific and limited. There is no need for additional medical prevention in examinations or operations. These measures are taken to protect both the healthcare staff and the patient.

It is a crime to turn HIV-positive status into an income area and to provide healthcare access for persons living with HIV at exorbitant prices.

## 6.4. Pharmacies

The prices of drugs used in HIV treatment are around 3000 TL per month on average. Medication cost; is covered by the state within the scope of SGK, GSS and green card. The income of drugs gained by the pharmacies is much higher than other drugs that are routinely purchased. Due to the apparent economic reasons, pharmacies may pay special attention to those living with HIV. Persons living with HIV generally prefer pharmacies that are far from their homes or workplaces due to fear of disclosure, which makes their lives difficult.

Regarding pharmacy routines, the participants stated their experiences as follows:

**KAA:** *"I looked for a safe pharmacist for a while to start taking medicine, but I wanted this pharmacy close to me. I saw that the pharmacist close to me came to the hospital park where I was treated, even though the pharmacy was far away, and distributed food to stray animals. The fact that the pharmacist was doing this gave me confidence and I went to that pharmacy and bought my medicine from there. I have been buying the drugs from there for 5 years. By the way, I never had the medula system shut down. I see it as a place where I can do activism. I provide visibility. By the way, I think my pharmacist is financially interested in me, I guess that the pharmacist pitied me after I got my medicine and left."*

**İAO:** *"I had no problem with my pharmacists. They even reminded me of my specific medication times. They were putting the drugs I was taking in two layers of bags. But something happened during the pandemic process: I woke up one morning and when I looked at my phone, I saw hundreds of messages. I was added to a group named "HIV positive persons". I looked at the group and there were 140-150 HIV-positive persons. Everyone's numbers were seen one by one. Persons were sending messages saying "We will sue you." I got worried and immediately left the group. If one of those numbers had been in my phone directory, I would have seen them and they would have seen me. There were no persons whose numbers were in my phone directory, but when I looked at the group to see what it was, I saw persons whose profile picture was visible to everyone, and I knew some of those persons from the dating apps. Such a sad situation was experienced due to the pharmacy."*

Lack of ethical information and respect for personal privacy can lead to violations of the right to protection of personal data by the pharmacists. The possibility of disclosure of those living with HIV can appear at an unexpected time and fields. Since there is no standard approach in pharmacies, persons feel obliged to choose the pharmacy carefully.

**IYE:** “*There was a pharmacy. Friends at the association recommended me. I went there and they offered me drinks. They did not question anything. They made me wait until the other customers left. Then they spoke to me. My pharmacy communication started safely. I just changed my pharmacy twice. The current one is also fine. Pharmacies used to behave badly. They refrained from dealing with us until they saw the profit brought by the drug... Ultimately, by selling three drugs, they get a huge profit equal to hundreds of pain relievers. That is why they start to approach us well. If there is money, there is peace. Although they develop a reflex in the first place, when they learn the percentage of profit, their attitudes completely reversed, but I still hear cases where the privacy of patients are violated. A portfolio of pharmacies providing drugs has now been formed. They have a list. As pharmacists move, they maintain their customers.*

**IKH:** “*I did not have any problems with the pharmacies. They even show interest due to the profit. They even called during the pandemic process. This interest is fine as long as they do not violate my boundaries. I have just a concern about the fluctuation in drugs towards the end of the year due to the raise in exchange rate of US dollars. Will the state stop cover these? I am concerned about that.*

**İÇB:** “*I went to the pharmacy opposite the hospital and bought my medicine. It is an expensive drug and therefore I am an expensive customer. They behave a bit as if I am privileged. For example, they shipped my medicine to the city where I am. I cannot dare to ask questions. When they ask questions, I get angry with them.*

**İDE:** “*My pharmacists were wrapping my medicines and putting in a black bag. On the third time I warned them not to do this. It is like buying pantyliner from the market. They did not do it again, but I know they did it to others. It is also true that they did a good thing. They have an apprentice. When he sees queers in the alley, he approach and advertises the pharmacy. He did not realize me at first; then when he saw me*

*with my partner, he came to me at the end of a year. He introduced his pharmacy. I started an argument. Our drugs are not very easy drugs. It is necessary to be close to the hospital. I could not find drugs during the pandemic process. I had to search for it."*

It can be a negative for open HIV-positive persons when pharmacists give the drugs by putting them in two plastic bags or black bags, which can be called good to ensure confidentiality. While these practices help the privacy of those living with HIV, they may also cause blocking of views for someone who are open.

**IAE:** "First I went to the pharmacy close to the hospital. I would not think that I could be so privileged in a pharmacy. They offered tea and said they could bring the medicine home. I did not trust them. I gave up going there. I went to another with the recommendation of my doctor. They were also extremely concerned. After one or two months, I got a message. They said that they brought my medicine, but they could not reach me. I wrote them that I do not want medicine right now. They said me sorry they made a mistake due to name resemblance, tried to have a conversation with me. I think this was the person who is the owner of the pharmacy, because the name of the pharmacy is the same with his own name. He wrote me "I do not think this mistake is a coincidence. I think we should meet". I said, "Ain't you a pharmacy worker? Is this how you communicate with your patients?" He said "Do not be silly, I just felt so "positive"" I said, "You have looked at my diagnosis apparently therefore you are trying to communicate with me, that is not ethical". He said "What are you accusing me of" and he blocked me. I feel like he thought that he can approach an HIV-positive woman who feels lonely as trying to show that he understand her. It is very sad really. I did not file a complaint. I had no strength anyway. I continued to buy from that pharmacy again. There was a very sweet woman there and she was very interested in me."

During the interviews, the comments of the participants towards the pharmacies were generally positive. What is striking about this positive approach is that the profit rates of HIV drugs are relatively high compared to other drugs. Pharmacies act with interest to those living with HIV when the rate of profit draws their attention, put their medicines in black bags and ship them if necessary.

While determining HIV policies, it is absolutely necessary to discuss the measures required to prevent discrimination and harassment in pharmacies and to provide sanctions in case of violation of personal data confidentiality by pharmacy staff.

## **6.5 Social security and insurance**

HIV drugs are covered for green card holders and for working and retired persons by Insurance of Social Security Institution for in Turkey (SGK) and for the others paying monthly premiums for healthcare within the General Health Insurance (GSS). Persons under the age of 25 who have health insurance through their parents may have a problem of disclosure to their parents. In addition, private health insurances do not cover HIV; therefore, those living with HIV can be victimized.

The comments and experiences of the participants on social security and insurance are provided below:

**KAA:** “*Three months after diagnosis I started to pay GSS, and in fact, I had to deal with this whole process alone. Someone was saying mechanically you shout do it, do it, but while I was dealing with my process but this hurts so bad in my heart, I was struggling. I remember those times were like that. I am still covered by GSS*”.

**İAO:** “*I pay 80 TL per month for GSS. I used to benefit from my family's insurance since I was a student before.*”

**KEK:** “*Since I am under 25, I have health insurance due to my father. This situation is also troublesome. A friend of my father is a pharmacist. My father found out how many times I got an appointment from which polyclinic. I think he learned this from that pharmacist. My father told me "Tell me if there is anything". I think the problem is that the pharmacists share this.*”

The appearance of the phrase: infection polyclinic on the leave papers and health reports of the working HIV-positive persons, the fact that the parents of the individuals who have health insurance through their parents can see that the examination fees are deducted from the infection clinic, and the pharmacists can access similar systems, are risking the privacy of those living with HIV on the basis of health insurance.

**AAA:** “There is a health insurance law for foreign students. According to the decision taken by Turkey in 2013, one can benefit from GSS by applying within the three months after registration to university. If you missed these three months, they officially leave you without any safeguard. So I missed these three months. I came to Turkey newly; I did not know what SGK, how to apply, etc. I received the diagnosis one year after my arrival and I could not benefit from the insurance. I always begged them to prescribe medicine for 6 months in my country. I could not afford these. Every three months I was traveling by bus, to my country and it took 36 hours, 72 hours in total albeit it is close. Aircrafts are already expensive. I also experience the tension of bringing medications across borders. I started my master's program in September and had health insurance. Sure, it is possible that they cut that too. My insurance will end in August. It is a year for foreigners. A law passed recently, if you received the diagnosis before insurance procedures, the insurance will not cover the medications of your chronic diseases. Because of this, many persons' medication was stopped. Mine is not cut yet, but we will see it in August.”

Health insurances for foreign nationals can be compelling for foreign nationals and foreign students with chronic illnesses due to the new legislation and laws. Therefore, foreign nationals cannot enjoy the right to health and cannot get the drugs in Turkey.

**İEY:** “I had a problem with insurance. I started in the association after I quit my job. I also got benefitted from unemployment insurance. I had no problem. Of course, those who are liable to Bag-Kur used to have problems. Or, you could not get a green card if you had a car. GSS is very comfortable. I wanted to have a private insurance, like life insurance. I answered yes to the chronic illness question. They said they cannot accept the policy. We were talking on the phone, the conversation was not face to face. They said the policy does not cover HIV. I could not get that insurance. I could not benefit from what everyone benefits because of HIV.”

Private health insurances still do not cover HIV today and do not provide insurance for persons living with HIV. This situation indicates that persons living with HIV cannot enjoy equal rights with everyone else and their right to health are ignored.

**İDİ:** "I have SSK. That is why I do not have a problem."

**İKH:** "Formerly, I got benefitted due to my family for a while when I was under 25. After I start working, I benefit from my own insurance."

**İAE:** "I had my own insurance while working, but I recently resigned and I benefit from my father's again. I am lucky about that because of my biological sex."

**İÇB:** "I am currently working. I am insured due to my job. My insurance has always continued."

**İDE:** "Right after I finished my education, I had a problem in insurance, but it was resolved immediately. It was resolved in 3 minutes or so. When I go to get approval from my family physician for work, I was asked if I have any chronic illness. I said I am HIV positive. The doctor was hesitant because the doctor did not know what to do. Then we sat down and searched from the computer. We are fine right now. The doctor is learning with me."

The problems in terms of insurance experienced mostly by foreign students and refugees. Foreign nationals, foreign students and refugees are concerned about their insurance being cut and not being able to access medicines with the new regulations.

## 7. | Institutional and political aspect of HIV

### 7.1 The attitude of the political authorities and public officials

Persons living with HIV face various discrimination and violations in very fundamental and vital issues such as access to health, access to justice and right to work, and are deprived of human rights due to these discrimination and violations. Despite this situation, international human rights are not guaranteed by the authorities and institutions. This situation breaks the trust of persons living with HIV in national institutions and authorities. For persons living with HIV, even the national institutions, institutions having the duty of providing justice can be useless, risky or victimizing.

The situation becomes even more critical when it comes to “LGBTI+ persons living with HIV. Persons are subjected to “multiple discrimination” by institutions and authorities due to their HIV status and their SOGIESC. When also disability, age, and refugee status are added, discrimination becomes more stratified. In that regard, enjoyment of the services by LGBTI+ persons living with HIV is restricted, prevented or can be only possible with extra effort. This situation reveals that institutions shall establish principles such as equality, accessibility and transparency that they are liable to.

One of the most recent examples of discrimination or hate speech in which the perpetrator is a public official is Friday sermon called “Ramadan: Patience and Educating the Will” dated 24 April 2020; where President of Religious Affairs, Ali Erbaş stated regarding those living with HIV as *“O people! Islam accepts adultery as one of the greatest harams. It condemns the people of Lut, homosexuality. What is the wisdom of this? It is the wisdom of this that it brings diseases with it and extinction. Hundreds of thousands of persons each year are exposed to the HIV virus caused by this great haram, whose name is adultery in the Islamic literature of illegitimate and unmarried life. Lets fight together to protect people from this kind of evil.”*

With this statement, the President of Religious Affairs (Diyanet) has targeted persons living with HIV, LGBTI+ persons, and those in unmarried relationships with a single sentence. Moreover, as it is known, HIV is a condition that concerns not only LGBTI+ persons, but also all human beings regardless of anything as its name stipulates (Human Immunodeficiency Virus). Homosexuality or being in unmarried relationship is not directly related to HIV. The opinions of the participants on this current issue are provided below:

**KAА:** *"For example, the voice raised up to Diyanet's statement on HIV was very weak. HIV-positive LGBTI+ persons are more vulnerable group as a subgroup. I do not like saying "Leave the fight to the subjects". This is not a fight to be left to the subjects. Maybe it is not strong when there are no subjects, but all persons need to break this understanding in the first place in order for the subjects themselves to exist. This statement of Diyanet should raise up the voices as strong as it is raised up on the issue of alimony. Just as it blesses the institution of the family and prohibits abortion, I think the state imposes a single relationship style, which is shown by this approach on HIV. I think at such a point feminists should stand up, as they did for abortion. I have been questioning where the Diyanet is in my policy anyway since a long time ago. None of these state institutions represent me. I say this not only for the Religious Affairs, but for all institutions of the state. The power itself does not represent me because I am so used to living without a state. I feel I do not belong there at all. I never trust any of them. I think my struggle is very valuable. I think everything not touched by the state is valuable. LGBTI+ organizations are one of the organizations that form their own policies without the touch of the state. The state will not produce the studies we conduct on behalf of us anyway. What I am worried about right now is the current power which is an authority uncomfortable with the legal system. If Turkey had not been in the legal components itself, would it never have wanted HIV-positive persons not LGBTI+ persons. That is why nothing is wanted on it; the politics, science, training on sexually transmitted infections, nothing. Apart from reporting us, they had to provide us something. If it is doing something, it just does it because it has to. That is why I do not trust state institutions and any of the authorities."*

The opinion that the power and the state do not represent the subjects themselves, not only covers HIV, but also covers SOGIESC. In a system that does not produce facilitating mechanisms for LGBTI+ persons and

those living with HIV, those who are the subjects of both have to create their own practices and can shape their lives in a way that they do not need a system that they do not trust through these practices.

**içB:** “*I am a citizen of this country. I have served this country. I paid my taxes. I am a part of this country. I live with HIV and there are thousands of persons living with HIV in Turkey. I could not go out because an institution I gave my taxes for targets me. After this statement, persons make their statements on social media. You meet the society there too. There is a bitter reality. When I go out, I have no security of life and property. I feel it. They say that we brought the corona, HIV, and they will hang us and kill us. How can I go to the market? I felt incredibly bad. Even if I say I do not care, I actually do care. They think that we should pay for their medications for them not to be around. There is no public ad on HIV on TV. Education is not provided in schools. The word HIV is not spoken on TV. You stick a lot of stickers on the cigarettes. So why is HIV in such an unspeakable position? The medical treatment is not enough. Will not they ever be interested in any way with the social situation? This is not a one-sided situation. Is there no HIV-positive working in the Ministry of Health, no HIV-positive ministers or members of parliament? I never trust any institution in Turkey”*

**İAO:** “*Diyanet made us look dangerous with its last statement. We are not a threat to society. There are persons with bad will in every spare of life from all status. As HIV-positive persons, most of us are conscious. Being judged this way ostracized us from the society. In my both identities, I have become afraid to go out after the recent violence. I have become afraid to touch a person. If I had religious friends, maybe they would have listened to that statement and feared me. It is not nice that he dragged me down in the eyes of my friends. Frankly, I do not think other state institutions are different. I do not trust institutions at all. I think even the healthcare staff are talking between each other on that. This situation feeds the appetite of my anxiety.”*

**İDİ:** “*I think they saw us as the cause of the pandemic. Diyanet's statement was horrible. Queers have struggled with this stigma for years. They consider HIV as “gay cancer”. Diyanet is telling such a serious thing from the very top; it is like a news on a satirical magazine. Not only LGBTI+ organizations, but also women's organizations, bar associations and leftist organizations had stand against that. Y say there is still a kind of*

*opposition fortunately. Being queer means the bed of nails. I appreciate those who dare to embrace it. One way or another, I guess the healthcare system is the most functioning system in Turkey. We have free access to the medicines. Maybe it is exhausting until the drug phase, but after the chronic disease is identified, it returns to a routine process. At least they do not exhaust me. I am getting an appointment and I am not even undergoing a registration right now. I get an appointment the day before, I receive an automatic confirmation voice record on my phone. When I go, my name is on the screen directly at my appointed time and I am not dealing with anyone. If I am not going to the lab, I leave the hospital in 15 minutes. It is also important that the laws protect HIV-positive persons' right to privacy. For example, a friend of mine had the Medula system shut down. This is a good option. In general, however, I do not trust institutions. I have more trust in opposition institutions, but there are times when I feel insecure with them too.*

**KEK:** *"I do not have an idea on the general activities of the Ministry of Health, but the thing that made me happy was that I took the medicine for free. And that is a good thing. I do not know how it is in other countries, but that was the only thing that I liked. But they do not raise the awareness of the others. There should be adequate awareness raising on HIV. Current data are inadequate as testing is not provided. This needs to be increased. I normally did not take Diyanet serious. The last comments upset me a little. We are already experiencing difficult things. I live alone in the apart-room and when he made this statement, it made me feel very uncomfortable, upset. He sees HIV as a homosexual disease, cursing homosexuals. An institution that should not exist. Or even if it exists, it should leave us alone. Therefore, I do not trust institutions. When I was diagnosed, a file was being prepared for me at the hospital. They asked me questions. "How did you get infected? Is it because heterosexual, homosexual relation or do not you know about it?..." I do not trust institutions because of what I was thinking at that moment. I wondered if this question would challenge me in the future. I thought it might cause me to be exposed. They do not build trust".*

According to the Clause A of Article 21 on Right to Respect for Privacy of Chapter 4 of the Patient Rights Regulation; medical evaluations regarding the health status of the patient are carried out in a manner that preserves the confidentiality. According to the Clause B of the same Article diagnosis, treatment and other procedures that require direct con-

tact with the patients are carried out preserving reasonable confidentiality. Accordingly, HIV diagnosis and treatment should be handled in a confidential environment, and even prescriptions should be regulated by a coding system. However, despite the regulation, unfortunately, the practices can violate this privacy. Due to such disruptions in the health system, those living with HIV cannot encounter safe environments and this may negatively affect the psychological status of the subjects.

The Ministry of Health provides free antiretroviral drugs within the scope of insurance in accordance with the social state principle and its obligations on human rights. However, updated information on HIV is not provided to citizens and immigrants, responsive diagnostic studies regarding the specific conditions of different communities regarding HIV are not carried out and HIV diagnoses are increasing day by day. This rapid increase causes concerns among those living with HIV about to what extent the state will be able to cover the medications in the future.

**AAA:** *"I was shocked when someone who can reach to a wide range of audiences embellishes such hateful phrases while reinforcing the existing hatred. It has increased the discriminations enormously. When I search for the term "AIDS" on social media, I see terrible articles, highly incomplete studies. Especially those conducted by the Ministry of Health. "The fact that HIV-positive individuals do not have regular health checks is one of the most important reasons for the spread"; they said. You are making this statement but do you inform persons? Using this phrase without setting up any mechanism is incredibly repulsive. You do not support anything, you stop the foreign nationals' medication, then you go out and make this statement. It is irrational. That is why I do not trust institutions."*

In accordance with the amendment made in the Law No. 5510, "**the prescriptions of foreign nationals will not be covered by the institution regarding the chronic diseases existing before the date where they deemed as the GSS holders or their dependents.**" This phrase has been included in the law, this prevents the foreign nationals from accessing drugs if they are diagnosed before the start date of their insurances in Turkey. Due to this obstacle, the foreign nationals experience difficulties in accessing drugs.

**İDE:** "Diyanet's statement covers also the queers to some extent and this upset me even more. Since HIV is also a matter of the World Health Organization and straight persons as well, I think they cannot give up the rights they give right now. Of course, these are the ones related to me ... They already take the rights back with regard to the refugees. Whenever this issue was considered in the agenda of the Ministry of Health, it is still the same. It can even be said they are consistent, but we are not looking for consistency. I find it strange that free access to medicine seems to be a magnificent situation. I do not like it. In a country that is in the process of EU harmonization, the medicine of course shall be free of charge. They take every step as a necessity. Regarding which obligation they sign the Istanbul Convention, they provide HIV-related services in line with this obligation. They will discard it at all when it intersects with their policies."

**İEY:** "They describe something from where they stand by referring to religion. What they describe cannot be as such, it is a scientific truth that HIV is a health condition. While there are already myths about HIV, it is unbelievable that someone who is in the field of producing discourse to discriminate persons. I sometimes overhear the discussions on this topic. They say "Morality is broken, our youth is destroyed. They give persons strength and courage. Sometimes I even feared in the shops, I was buying whatever I need right away and leave the places immediately. This is a statement that will further increase the mistreatment against persons who are open and proud. The Ministry of Health, on the other hand, does not have any activity to inform persons living with HIV or the other persons. In particular, they do not regard the LGBTI+ community and HIV issue separately. For them,, HIV is a problem for LGBTI+ persons. They broke this slowly. Now they say, it is "Everybody's problem", but they do not have any activity. They say, "We cannot reach key groups". So why cannot you reach key groups, namely LGBTI+ persons and sex workers? because you are not inclusive. On each 1 December, "Why are our numbers increasing?" is discussed. Well, if you leave it to three or five NGOs, it will increase of course. They cannot name LGBTI+ persons in the studies, even in their campaigns. Because if they name it, they will accept that we exist. They refuse it. They slowly had to care. Of course, it is also caused by the pressure from abroad. I do not find sincere what has been done since we are disregarded. But when you have 200 thousand persons for whom you need to give medicine ten years later, you will say that citizens should contribute. There are works done, but they

*are not done in a desired speed and honestly. So I believe in what is done, but I do not trust completely.”*

Continuing diagnostic studies for “key” groups, such as LGBTI+ persons and sex workers, ensures easier identification regarding current diagnoses and rapid dissemination of current HIV information among these groups. On the other hand, the Ministry of Health does not carry out studies on key groups and cannot establish comprehensive communication with these groups due to its distance and prejudice against key groups. Today, studies for key groups are carried out by LGBTI+ organizations and associations working in the field of HIV, which we can call “positive organizations”. At this point, it can be said that it is ensured that the key groups to have knowledge on HIV and human rights to a certain level, while those other than these groups - such as cispersons and straights - have a much more limited access to knowledge on HIV.

**İAE:** *“HIV is not seen as any virus. It contains sexuality and LGBTI+ persons. That is why for society it is like boogeyman. We have to overcome these taboos first. My mother told me something a few months ago: “ISIS members are visiting homes and injecting persons with AIDS” HIV is a tool for horrifying persons used by religious groups. It is used to intimidate someone. It is always shown as the weapon of the wicked. “The process in your country is easier than the process in our country” said someone living with HIV living in the UK. “The drug taking process is easy”. That the insurance process is available is also a factor. Of course not to make life easier for persons living with HIV, but this process works in HIV treatment. Since they will have to talk about LGBTI+ and sexuality when they talk about HIV, it is the most convenient stance for them not to talk about these issues. They just think they can end it by cursing.”*

**İKH:** *“With the statement of Diyanet, we saw how the authorities put us in the same equation. We are all in there. It does not matter who we are in the eyes of the power. That is why we are in the same equation, we have to think like each other. That is why we need to develop discourse in every field while working. There is a hatred rising against LGBTI+ persons, but it has never been directly targeting HIV positives before. According to them naming us “perverts” is not scary at all. But even though my mother does not know that I am gay, she knows how drag I am. Your targeting of gays makes my mother uncomfortable. This is not one group. We are all in life. The words are dull then. When this is not*

enough, he says, "When you do this, you face this virus"; in such a tense Covid-19 period. HIV is given back to fagots as a punishment. There is no social correspondence of this. How can persons go to the hospital after these statements? How can they come out? They are discarding us. No organization has the power to facilitate such a process. They are afraid that the conservative world will be ruined. They do not want to normalize that persons have sex, but persons do sex already. This is the case whether you distribute condoms or not. Quite the opposite of it will be easier in financial sense. Even this can be bearable for conservatism. We want PReP to be talked about, but there is a state that does not even maintain condom activism that we sweep aside the most. I do not trust institutions, administrators and the system that do not know me, target me and exclude me in the system. There is no systematic policy from bottom to the top."

Human rights of persons living with HIV do not build a positive agenda in the eyes of society and politicians, and the discrimination faced by persons living with HIV is also ignored. On the contrary, while provocations by public officials reinforce existing prejudices, it becomes even more difficult for persons living with HIV to reach their rights and to be open about their status.

Although the PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis) are the important and economic tools in preventing the transmission of HIV, no comprehensive study are conducted on these in Turkey. In addition, access to these drugs may be possible under certain conditions. The condom, which acts as a barrier to HIV as well as to other sexually transmitted infections, is sold with expensive prices and public policies on the spread of condom cannot be implemented due to conservative views, just as in PReP and PeP."

In summary, the Ministry of Health, all public institutions and organizations, the private sector, academia and media shall update their HIV and human rights approaches in the light of universal principles; need to pave the way for those living with HIV to enjoy their fundamental rights such as health, employment, participation in public life, access to justice and protection of personal data. In doing so, the expertise of LGBTI+ organizations and positive organizations should be consulted. Only in such an approach the state can fulfill its human rights obligations to

HIV-positive persons, and HIV can be spoken openly and becomes a public health issue generating inclusive solutions. Ultimately, this does not only concern HIV+ and LGBTI+ persons but also the whole society.

## 7.2 Labor life and military service exemption process

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Persons' HIV status does not affect their job. In fact, those living with HIV can specialize in many professions such as cooks, teachers, lawyers, healthcare professionals and provide their expertise in their professional lives. Regardless of the profession, although HIV does not affect the job, those living with HIV may face many problems in their labor lives. During the job application process or while the employment continues, the HIV status of the individuals is exposed through the unfounded tests that are requested and the employment of those living with HIV can be ended with various excuses. In the work environment, persons may be disclosed to their managers, physicians at the workplace, colleagues, and they may have difficulty in come out in their labor life due to the fact that the work environment is not inclusive. While persons have difficulty in obtaining permission from their workplaces for routine hospital checks, they may be exposed to discrimination, hate speech, exclusion, isolation, and violence at work due to military service exemption certificates. According to the report on violations of rights covering the period between August 2008 and December 2009 written by Positive Living Association, while the rights of persons living with HIV are violated in the field of health with the highest rate of 33%, this rate is followed by violations in the workplace with the rate of 24%. The association reported 19 cases of violation of the right to work in the same report.

The process of exemption from military service has been assigned to state hospitals with the closure of military hospitals after the 15 July events. At this point, those living with HIV and LGBTI+ persons may face many problems. Public hospitals do not have practical experience in preparing exemption certificates for persons on account of their HIV status or SOGIESC. This situation becomes even more apparent in less populated areas. While persons are faced with the possibility of disclosure due to their identity or status in less populated areas, HIV or LGBTI+ phobia of healthcare staff in general may become more clear when it comes to military service.

The participants we asked about their experiences in labour life and the military service exemption process have provided the following experiences:

**KAA:** “I cannot work due to my identity. My constant obligation to express something made me to leave the workplaces. In the workplaces I work, the issue has never come to HIV, but because I was an activist and have a discourse, I lost my job. I have not yet pursued for military service exemption. I am afraid. There were many times I reversed my decision on applying. For now, I have chosen myself a family physician. I started my process for exemption, but due to the pandemic, I had to postpone my process. Military service was one of my worst fears. Weapons and military service are traumas for me. I was worried about “How will I perform the military service?” When I found out that I am living with HIV, the fact that I can have an option to be exempted from military service is relaxing.”

**IAO:** “I had a year of work experience and a few internships. I graduated recently and I will find a job and start working in a month or two. They did not ask for a test at my first job. They just wanted physical therapy related to herniated disc, because I was working standing. No such test was requested during my internships. Only during my last internship they had me sign a document stating that the private information of the staff can be shared with third parties when necessary. Normally, they wanted a test at that workplace, but they did not ask us as we started our internship there as a group. Actually I applied elsewhere for an internship but I did not go there because they wanted a test. Because I thought that if this information shared with the school, I would not be able to finish it.. I never came out to my schoolmates or in workplaces. Workplaces are places where everyone should be perfect and under constant pressure. They are not inclusive and LGBTI+ friendly. If I had came out LGBTI+ maybe I would not have had much trouble but I could not come out HIV in any way. When I needed permission to leave, I always made up something else to get the permission.”

**IDE:** “I had only one full time job experience. I have not came out but they know the articles and news I have written. I am being monitored. Before I worked, I was more anxious. I can easily get permission to leave. It is easy because it is a private sector. I do not have a problem during the process as nobody can understand me from my physical appear-

ance. There is also a corporate policy and the policy is inclusive. The institution is a little careful because of its work and we can have conflicts and reconciliations in such places. They are open and reconciliatory. It consists a large team, almost all of them are women. I also think this has an advantage. In the matter of military service I actually got a referral to the family physician, but due to pandemic, my exemption process was interrupted. I want to get it and close the process quickly, as soon as possible".

Avoiding various life practices due to potential discrimination and thus violation of the rights is a common situation for LGBTI+ and HIV+ subjects. In order to avoid discrimination, persons do not enjoy their rights, shy away from and may face situations such as not being able to perform their profession, benefit from services or even claim their rights. Past experiences of discrimination, primary and secondary traumas and prejudices are among the main sources of this situation.

Another remarkable point is that persons stated that they can come out at a point as LGBTI+ when they have to, but when it comes to HIV, they will never do so. It is understood from this that society's prejudice against HIV and HIVphobia force persons into a completely different discrimination framework.

**I<sub>EY</sub>:** "I always get the permission to leave by using my mother as an excuse. I have never done such regarding my own health problem. Of course, I am obtaining it very comfortably where I work now. Persons are also uncomfortable lying because some places question them in detail. They can request a medical report. Persons have no obligation to declare. Administratively, every employee already has one or two days of administrative leave. There are persons who use their annual leaves to prevent the suspicions. There is such a thing as occupational health and safety in our lives for the last 5 years. As a requirement of this, the workplace doctor is required to be informed. Tests for infections are being ordered, especially if they are in the healthcare or food sector. This did not exist before. Now private companies and firms have included HIV in tests. In this situation, there are persons who have difficulties. For example, one of my counselees, a public healthcare staff refused the test request and turns off the Medula system, but they are pressuring this person. They are dismissing persons somehow in the private sector. There is trouble, of course. They do not say that it is because HIV but

*somehow they do not employ them. I did not have any problems with my former workplaces. When I first learned that I am already living with HIV, I left and started working in the association. Where I am right now is okay in terms of inclusiveness. I got the military exemption certificate for a long time ago. I was constantly delaying. Photographs were requested in those days. I went there without being feminine and tried to tell the psychologist. Although exemption result was in the personality inventory test, they constantly wrote referrals because I did not want to undergo an anal examination. "You do not want the photo, the video and the anal examination, how can we prove it?" They said, "Do not you trust psychology? How can I deceive a science?" I said. They said, "We have to test physically too, the process will not be over without that". Finally I accepted. The doctor put on the gloves and checked me. In the report, as I guessed, the anal muscles are found fine because I did not play passive. I think they were convinced when I accepted the examination, so they provided me with the report."*

**KEK:** *"I have no job experience since I have never worked before as a student. But when I first learned about military service, I was upset that I could not perform military service because I did not know how to explain the reason to my family. They are not understanding persons and regard the military service as patriotism. They are nationalists. That is why I was afraid, not knowing how to explain it to my family, thinking how it will affect our communication. Right now, my communication with my family is better and they respect my decisions. Now I can even say, "I am glad that I will not perform military service."*

**AAA:** *"I do not have insurance. Because I am a foreign national, they do not do it because of my work permit. The places where I worked were in the cafe-bar sector until today. Now I am doing foreign trade in a medical company. There was no test request. I am not open as positive but I am open as LGBTI+. The company is in another country and business groups in Turkey I worked is pretty good. I do not have any problems with my sick leaves. We work freelance. When I say, "I am not going to work today", I do not work. We are more comfortable. Since I am HIV positive, military service is not possible in my own country. As I know they are writing a code in my country; there are persons who can understand that I am living with HIV through that code. Because my father is a police officer, my brother is a soldier. They will probably understand."*

The military service process is a process that is expected to be performed by the family, the circles and the potential work places. While those living with HIV are already exempted from military service due to their status, LGBTI+ persons due to SOGIESC, they face many discriminations during this exemption process. Moreover, if persons are not open as HIV+ or LGBTI+ persons, they may be subject to discrimination in family, circles and labour life since the reasons for exemption are thoroughly questioned by them.

**IDi:** “Once there was a test request. It was not when getting hired. It happened while I was at work. My heart was beating so much. I ask my friends, “What should I do?” We went to the cafeteria. Doctors had set up the stretchers. An examination was done everywhere. Then, if there are six different apps, it is ok to undergo four. You do not have to be tested for the two remaining tests. I said “I am afraid of needles” then they did not take my blood. I was saved. My colleagues, managers, and workplace doctor never know my status. It is not an inclusive place. The place where I work is by no means inclusive. But I have no problem getting sick leave. I deceived them by fabricating a health problem when I first employed. The doctor told me “Use this excuse”. I use this. Sometimes it coincides with my day offs. I go back and forth for a few hours. By the way, I performed my military service. I had not been diagnosed with HIV yet. My workplace is a difficult place. The issues that they talked about among themselves are terrible, since I have an activism identity. You cannot always be silent. Some moments happened where I cannot hold myself regarding any rights-based issue. They know my attitude. I tell them when these kinds of issues are brought up. They know I have a separate universe from them, but they do not know which universe I am in”.

**IKH:** “When I was looking for a job, I did not apply because they asked for the chronic illness in some processes. I have been in a position staying away. I have never confronted. Blood tests were requested two times before the employment. They did not tell where they use it. I gave it unknowingly and I was worried. The workplace asked me to give it in their own polyclinic. I had no escape. I was thoroughly worried. As a matter of fact, it was not related to HIV. Therefore my status was not exposed. There were some persons I shared my status with. That friendships at work also included a social friendships. I came out to some like that. On the other hand, I go to the hospital every three months taking a half

day leave. I shared this with the persons who can handle my absence. I did not hear any reactions from them either. There were also those who started thinking about HIV with me more, and those who did not ask questions by avoiding from bothering me. During the pandemic process, I came out to my manager because I did not want to go to work. I trust the medicine, I trust my process, but there may be something that I cannot control. Maybe unexpected things might have happened because I cannot go to the hospital. I could have been risky because we could not see it. The doctor did not give me report at the hospital. The doctor did not count this as a chronic illness. My treatment was actually interrupted. We were not in an equal position there, as the doctor told me. Then I came out to my manager and asked for their support. It was fine too. My manager knows right now. Based on my own statement, the manager ran a closed process just between the two of us.

Even though I refrain from sharing it, I also want to share it. At some point HIV coincides something in my life, because I go to the hospital every three months. I let them know where I am going. It was really good. I have strategic coming outs like this. Before, my colleagues were guarding over me, they were handling my absence for half a day. At least everyone within the institution knows that they cannot exclude anyone. And that is a good thing. Maybe it is not like that outside the institution, but the staff looks after each other within the institution. I do not have a disadvantage as a gay person in my institution. I even have its advantages, but HIV is not like that, of course. However, they associated HIV with being LGBTI+, not directly through my HIV status. My discourse on HIV directly caused them to stigmatize me with HIV. When you develop a discourse, you stigmatize you.

I got my military exemption immediately. I did not want it to be an obstacle in front of me. I wanted to get it done in the process I was going to start to work. There, too, when you go to the branch, your personal information becomes an open information. You are already in the same place as everyone else. Persons ask you "Why are you getting an exemption? ..." It is a process that have too much bureaucracy in it. It is unsystematic. They make you run between places. The system is not ready for you. They do not do it for HIV+ persons and fags to be tired, but they did not prepare the system for you. They did it for HIV negative persons. They learned the process with me as if I was the first HIV positive person. I do not think I am the only HIV-positive person there. It is a big city also. The branch sends you to the family physician; then you were sent

to the hospital. Then the hospital says, "This is missing"; you are doing it again. There are situations that do not make you feel safe and force you to open. I took care of it when military hospitals were closed and the process was appointed to the state hospitals. You are seeing a committee last. They are pitying. It was very boring. What is the origin of this pity? Is it because I cannot join the military? Is it because I am HIV positive? I do not know. I wanted to ask "Why are you upset?"... Of course I did not ask, but their sadness was ridiculous. In the meantime, they asked me for my previous tests during that time. I got my past results. Then they retested me at that hospital. You can see it when you look at my past reports anyway. The state gave my medicine. If I am negative, the state cannot give the medicine. My workplaces did not formally ask me about the military service, but my superior asked me in our second talk. When I say I got exempted the superior was surprised asked the reason of it . We were talking in an illegal way. I said because I am gay. My superior did not know that persons could get an exemption just because being gay so got surprised and said "Is not that discriminatory?" I said I did not want to perform it anyway."

**IAE:** "They never asked for any tests at the institution where I work, but when I thought of applying to the municipality, I saw that they wanted an HIV test. I asked my friends at the association. They relieved me. When the pandemic intervened the process, I could not experience the process. If I were, I would work as a social worker. It has nothing to do with HIV. I told a person at work about my HIV status. That person could not ask or say anything, I think this person had no knowledge of these matters. Even asked me "Is it HPV?". I guess this person thought that I could not say I am HIV-positive openly, since did not know anything about it. But I did not experience any discrimination. My workplace is never inclusive. The owner was a religious man. He even warned me because of my piercing. They asked me if I use alcohol, cigarettes, what my political views are and whether I had been arrested before the employment. I was interviewed like a security investigation. If they knew my HIV status, I would get rejected directly. Even if they knew I am a queer, I could not stay there. My working hours were extremely good. I could schedule my sessions before noon or afternoon and we were working in our own offices. For others they sometimes had rumors and called them fags. I was trying to warn them as much as I could, but I usually isolate myself in the places I work. The community is such like that after all."

One of the biggest problems in the labor life of LGBTI+ persons living with HIV is the inclusiveness of the workplace environment. Although persons may sometimes share their SOGIESC and sometimes their HIV status, they may experience problems due to the lack of political, inclusive and updated language and approach regarding HIV or LGBTI+ issues in the workplace.

**iÇB:** "The schools where I worked were big schools. They did not ask for any tests. Only they reviewed my former experiences. I got diagnosed when I was working. When the medicine took effect, I started getting permission for tests. I took time off five times at regular intervals. After receiving reports from the infection clinic five times, they noticed that something was wrong. During the close of the day, they held meetings for me to tell them what happened to me. I also said that there was no situation affecting the school and that I would get over it after a while, and if they wanted, I could submit a report that there was no situation that would affect my profession. They continued to pressure me as if they were thinking about me; I had my entrance to work examination, but they told me that it was not done and sent me to the workplace doctor. The workplace doctor made a general examination. He handed a form and there was also chronic diseases in the questions. I checked none of them. Then he handed me a paper confirming the accuracy of the information I had given and I signed it. A week later the principal said, "You do not need to tell anymore, we know what happened to you. We are thinking of you. We have two offers for you. Either quit teaching and do paperwork in a room, or lets we pay your salary, do not come to school". I said, "This is a terrible discrimination what you are doing". I asked them to give me a day. The way back home that day was very long, very difficult for me. I tried very hard to get into that school. All my purposes had disappeared. Then I called an association. They said "Do not let them exploit you" It made a sense. I could not do paperwork in a room in an unreasonable place. Persons would question the competence of my teaching. I did not accept this offer and claimed my personnel rights with my salary. I told them I would not come. I did not go to school. My salary was paid until my contract expired. I thought I could be more creative when I stayed at home, but the house was worse for me at that time. When I was alone, I thought I am an unwanted and unnecessary person and got worried."

"Then I got an offer from another school. I went there. I passed many interviews at the school. Then I received an offer to enter the job and

accepted it. I prepared my documents. There was also my military exemption certificate. Human Resources while checking the documents and saw it and asked me the reason of my exemption. I jokingly said ask this to the TSK. "You have to say it" HR insisted. I insisted on the point that I did not want to say. Then HR said "Well, okay" and I signed the contract. I wanted a copy. HR did not accept "We will first have it signed by the board of trustees and then give you a copy". I went out and called me before I got home and told me that an examination was needed. So I called my doctor at the infection clinic. The doctor said "They cannot ask you about this, you do not have to declare it, I will provide a report for you if they push you further". Then I went to school. At first the nurse asked the standard questions and I said no to all of them, then when the reason of my exemption was asked I said I did not want to answer. "They will cause trouble for you" she said and referred me to the doctor. The doctor opened the medula system in front of me and turned the monitor towards me. "If I press the search button, I can see the health reports and clinics you have. You declare it yourself" he said. I told him that I am living with HIV, probably because he had already searched for me before I came. Thinking that he was a doctor and that he accepted patient confidentiality and knew HIV, I talked with him. The doctor said "I am dealing with such persons like you for thirty-three-years". I tried to explain to the doctor that I do not want to lose my job. I told him what to do. He said "go get me a report from the hospital stating that you are healthy". I said "No hospital can give me such a report but I can bring a report that it does not prevent me from teaching" I said. "Then you cannot work here", he said. I got a report; the doctor did not receive my report; I left it to the nurse. A week later they called me and said they do not want to work with me."

"I tried all the big institutions. I am now working in non qualified school. They could not find a teacher either. I went in there. When they asked why I was exempted, I said scoliosis. They immediately put the contract in front of me. I also had to work. I signed it and entered that school. It lasted for a year. Meanwhile, the pandemic started. That school kept calling us while all the schools sent their teachers. We were just sitting there as teachers. I was worried at first. I shared my concerns with the administration. I said I had a problem with immunity and I want to use my general administrative right to leave. I gave them a medical report. They also called and questioned my doctor at the public health center. Naturally, my doctor did not share the reason. The principal called me and said "the institution decided to sue you because you were not trans-

*parent at the time of employment." I said " ok, do it". They researched it, they did it, and I think they closed the issue because they knew they could not win, but they started a disgusting mobbing. They made me feel worthless. It was a difficult process. Then we started working from home. I did not see them at that time. Regarding salaries we had arguments for different reasons. I have opposed too. This year they tried to terminate my contract and forced me to resign. Now they sent me non-paid leave. I am stubborn right now. I gave up from the private sector. This HIV became an excess baggage for me... I thought I would feel more free in the private sector, but I saw that they search everything even my blood. They examine everything. They have a safe bell jar they set up for themselves and they do not want contaminated persons in that area. They see me as contaminated. They see it as if I am polluting their Arian state. That is why I think of the state institutions now. I need the money until I leave Turkey; that is why I am preparing for the exam"*

The transmission routes of HIV are clear: unprotected sexual intercourse, blood transfusions and transmission to baby in pregnancy. These transmission routes have been largely prevented thanks to current medical developments. While the HIV status of persons does not create any obstacle for them in their profession, institutions can shape the system for them and use it against persons living with HIV. HIV testing is an unfounded practice during employment or working life, and persons do not have to report their reasons for exemption from military service to the institutions. What should be measured is the success of the person in the profession. Moreover, phobic attitudes of the workplace environment negatively affect LGBTI+ persons and those living with HIV. Therefore, workplaces should be transformed into safe places especially for HIV+ and LGBTI+ persons and equality must be ensured with the policies to be implemented.

### 7.3 Life in school and education

Detailed information on HIV or sexually transmitted infections is not included in the curriculum of formal education. Sometimes, with very limited seminars, current and non-human rights views on HIV are provided to students, and teachers do not have sufficient knowledge on this subject. Today, even the out-of-date attitudes and discriminatory

attitudes of healthcare professionals on HIV are striking. The dissemination of current knowledge on HIV based on human rights principles has been undertaken by a small number of civil society organizations and activists.

Unfortunately, developments in the field of medicine are not widely known by the public, and the effect of HIV on health is still thought to be as in the eighties. However, those living with HIV can continue their lives as healthy as anyone with one or a few drugs used a day. Similarly, it is not known that the transmission effect of HIV with these drugs is eliminated. The responses of institutions and individuals to HIV are shaped by prejudices, and studies on the discrimination faced by persons living with HIV are unfortunately not being carried out properly. Nowadays, the inclusive policies on HIV, which has ceased to be a “health crisis” and has become a “social crisis” or “human rights crisis” due to prejudice and discrimination against persons living with HIV, are being implemented with very limited financial resources.

In addition to these, the education curriculum can cause the spread of false information. In fact, the out-of-date and discriminatory information on HIV feeds the prejudice of society and makes the lives of persons living with HIV difficult. Participants shared the following experiences on these issues:

**KAAs:** *“There is no place to get updated information on HIV. Medical language is not a community language anyway. While talking about HIV, we should talk about it in a little more simply way. I observe that we cannot explain U=U for example. “How can we express them more easily?” We have to consider this. Society’s knowledge is still limited to that basketball player died racked with pain. They are still afraid that they might have HIV with the syringe squeezed into the banana. Not from unprotected relationship. In the meantime, when I did not know about HIV were the times I was in (a non-governmental organization that has activities on HIV)<sup>2</sup> Then when I went through the process, I said, “We fooled ourselves”. By the way, I am a very distant person from school. I cannot go to school. I cannot exist in school and I have always gone to school to postpone my military service. The academy is not a place for*

<sup>2</sup> The name of the organisation is not provided here in accordance with the principle of protection of personal data.

me. (...) That is why I could not keep up it. When I found out that I am HIV positive, I stopped going to school at all. I took a week of sexual health training but only on condoms. I knew neither PReP nor virus nor viral load. I think the studies are inadequate, but even the smallest work can contribute something”

**IAO:** “In the health science class, I saw HIV for the first time when I was in high school. It was written that it is a sexually transmitted disease and there is still no cure. There was a fear created, or just a knowledge withdrawn into sexuality, and it seems to me now that it was something to prevent children from sexuality in their adolescent years. If the teachers are not conscious about this issue, the studies should be carried out with the help of the institutions. Teachers are not conscious about this either. Correct information cannot be given. National Education can receive support from outside. We are ignored, removed from society, and it is hard for persons to recognize us. I follow updated information from Red Ribbon and Kaos GL. Sometimes I look at Positive Life, but I guess the information there is old. I mostly search for it from foreign sources. I attended a workshop on HIV in the city I used to be.”

**KEK:** “As for my school life... I estranged only from a very close friend when he started to go and tell persons we never knew about the private life of another friend, who had a bad relationship with him. I thought “Will he tell about me too?” I panicked. If the school heard in this way that I am HIV-positive, I thought I probably would not even graduate, I would have to change schools, change departments. But there was not a problem because he did not tell. I am a graduate of a high school for teachers. HIV was mentioned in our health class, the instructor was already uninformed, but what was written in the book was also horrible. It was a book that explained that it came out as a homosexual disease and continued that way. The teacher was also unconscious, having a homophobia in this regard, we just get the lesson on sexual issues in a fast way skipping.”

Information in the books and on the Internet is terrifying. The stories shared even on the pages of the associations scare me. Persons should contact the associations themselves and get counseling. I have never encountered university studies. I follow all conferences but I have never come across anything like this. On 1 December, the HIV/AIDS conference was held once at my university. My doctor provided a speech there, but this happened once and never happened again. The doctor was al-

*ready speaking with his own language. HIVphobia was not mentioned there. It was explained and skipped. The relationship established with PReP and PeP is not enough. In this geography, persons resist not using condoms. They do not actually have to use it, but even when these persons have their own preferences, there is no information about why persons should use condoms. Persons do not know what a condom is. PReP and PeP are not spoken at all. I heard it was difficult and expensive to access. That is why the doctor asked me my previous medications when I changed my medication.*

*Healthcare staff is also not conscious. I have not had a problem with the doctors, but the nurses and other staff do not have enough awareness on this issue. The language they use is very important and affects persons. It is very bad for a nurse who takes blood to blame the patient for not wearing gloves when they should. I attended the workshop of an LG-BTI+ organization before on HIV. I learned many things there in general terms. Then I got another training from an HIV organization.”*

There is a limited amount of information about HIV in the curriculum and this information is out of date. The lack of up-to-date information, insufficient knowledge of HIV that is given to healthcare staff and not form human rights principles, paves the way for mistakes in practices and for difficulties faced in accessing health by persons living with HIV. On the other hand, when persons learn that they are living with HIV due to being misinformed, they may also inflict discrimination and phobia on themselves.

**AAA:** “*I had a problem like this at school: I told a friend. It was when I got a new diagnosis. Then that friend of mine did not attend school much. We could not come together. Years have passed, I went to another country with a project. When I came out to my schoolmate with whom I was staying there together, my schoolmate already knew, because the first friend I told to one, that one to the other and it was spread. I do not know the education in Turkey; education on my own country was only about preventing the drug use. I wish there were projects, we can approach to schools, even to universities. It would be nice if we could at least address especially medical students. I follow international news. Actually, I look at more empowering studies, because I think individually I can help one or two persons. I am trying to search for the things what I can do in that regard. How can I empower myself, how can we become stronger as peer*

counselors? I am thinking about it. I am tired, overwhelmed. Frankly, I do not know what kind of studies are there on these in universities. Still, for example PReP and PeP are not in our lives much, but many persons now hear about it. The HIV negative persons started to know about this. It is a good thing. Maybe they can raise up a voice. Awareness is raised. The awareness of healthcare staff is inadequate, they do not know. They are especially ignorant in the field of HIV. When I go to the tuberculosis dispensary for an x-ray, for example, the doctor become restless when he sees that I am coming from the infection. They are generally bad. They are very ignorant. I have been trained on this before. I received training on peer counseling."

In accordance with the principle of protection of personal data, HIV status of individuals should not be shared without their consent. Otherwise, there is a violation of the right to privacy. Despite this, HIV is seen as a tool of rumor-mongering and the status of persons can spread around. The concept of "consent" is essential in various areas as well as in the HIV field. There may be consequences of sharing the information of the persons with third parties without their consent, legal sanctions can be imposed. On the other hand, this situation is not ethical either. Persons do not have to share their HIV status with anyone.

**IYEY:** "Of course I consider the curriculum awful. It is still said to be a sexual illness and a deadly disease. AIDS is still considered as the deadliest of all blood-borne infections. They do not have such an ethical course on "How to approach those living with HIV?". Hence, HIV-positive persons are becoming a more vulnerable group. Persons use Google to learn about HIV. Of course, this is not healthy. If you do not know about HIV, you cannot question the information there. Photos and information on the Internet are horrifying. It is nice that NGOs have been producing information recently, but it is necessary for the person to obtain the right information at the right time. It is nice that young persons care about HIV. TOG/Community Volunteers Foundation has conducted good studies. It is very nice that young generations who will be in the field of health try to spread these rights. Of course, they are experiencing systemic setbacks. Rectors may not allow these studies. Young persons talk to each other between themselves I am sure, but PReP is something that you go and obtain with the same routine checks. Safe sex is still the most effective, condom is still the most important tool. I do not think Turkey will be able to provide the right to PReP for a long time. Just a few train-

*ing are provided to healthcare staff and this is insufficient. There is no affect on the rights of patients with the limited education they receive. If the teachers who teach the HIV-related infection lesson have a phobia, what the students will learn depends on them. In short, the teacher has to provide more information than the education on books. I got a lot of trainings. Those were about HIV and human rights. Associations also provide these trainings to those who want to get information."*

Antiretroviral drugs, PReP (pre-contact prophylaxis), PeP (post-exposure prophylaxis) and condom are the four most important tools to be discussed in the HIV issue. Due to the lack of education system, no information is given about these four tools. The education system cannot provide a pluralistic and human rights-based experience sharing on HIV. Due to the known sociopolitical environment, HIV-positive persons need to hide their status because there is no strong legislation and public policy protecting their rights. As such, persons use the internet as the first option to access any information on HIV. Whether the Internet will provide updated and correct information is a matter of luck. At this point, whether they live with HIV or not, persons can take wrong steps with the wrong information they get from the internet. The prevention of awareness raising and specialist studies organized in universities on this subject leads the new wrong steps to be developed.

**IDI:** "There is nothing smallest bit. Things that happen are also extremely phobic. Public schools are conservative. I never think that a comfortable seminar area is opened. Persons are learning from Google. There is infollution, but it is important to be able to recognize which ones are the correct information. It is also learned from social media or associations are called. HIV can only be learned through such things. Of course, those who want to be conscious do this. If they do not care, why should they investigate? Frankly, I do not know what kind of activities the student clubs carry out in universities. As I said in small cities, the situation can become more phobic, so healthcare staff can be more phobic. This situation is relatively less in big cities. This is something about seeing cases frequently. My treatment was not denied in many places. I had an operation, even told my doctor. The doctor told me to operate me, after everyone got operated and they would sterilize the room after me. These are things about seeing cases frequently. Even if you are educated, learning on the field is something else. I have not attended any training before. Maybe I joined some small panel sessions. I did not remember much."

Another issue that has emerged and worth to discuss is the limitation of the studies conducted in the field. Subjects living with HIV play a major role in providing updated, concrete and accurate information on HIV and determining the needs and problems of persons living with HIV. One of the best ways to get in touch with HIV is to listen to the experiences of those living with HIV. While it is not even thought that a person living with HIV can survive in the society, this situation can only be eliminated by the dissemination of inclusive and rights-based information and the creation of safe environments where subjects can come out.

**IKH:** *"At school I did not share it with anyone, at university. There was no one I could trust. It was a time when I was just coming out as a gay person and I was having difficulty with it. I did not think to say that I am HIV+. Since the places where I work are places with a view of human rights, it was easier for me to be open as gay there, but HIV is not like that. Nothing is talked about sexuality. Sexual health is not discussed. Even our psychological and physical well-being is not talked about. If you cannot find a place to talk and express yourself, it actually makes you unhappy in every way. Curriculum is not adequate in that regard. It does not teach things about us. On the other hand, it provides the wrong sources. While it should be the most reliable institution, you are trying to get information elsewhere. There is no use in this being unspoken. They were separating them as girls and boys in those trainings. They define sexuality with the opposite sex. There are more condom-oriented studies in universities. I can understand medical organizations at some point, but youth organizations should take the issue a little more rights-oriented. Now I guess they cannot do that either. It is not wrong for someone to do these anyway, but even this correct or missing perspective is not provided at the moment. Even the policies we call insufficient are not adopted by the universities. Training on infections provided to healthcare staff is not enough. If it were enough, I would not find suspicious the questions they asked. Once I attended a workshop. It was good too. When I started dealing with HIV, unfortunately I was already HIV positive."*

**IAE:** *"You cannot understand if healthcare providers got a training. "Could they not be aware?" I say, but they cannot get to this point without knowing the profession. Maybe they learned about it superficially in school. I think very different stories are told in those lessons or by prejudiced teachers. I remember a paragraph of HIV in the curriculum. A huge*

issue was explained in two sentences. Persons with active sexual lives obtain superficial information on HIV while exploring infections. They see the information "There is no cure". "There is no cure" sounds like you are dying. We cannot see HIV in any area. Although I am a political person, I only saw a few articles and events. Even though a cis-heterosexual person can share rainbow flags during Pride Week, while a HIV-positive person cannot share a red ribbon on 1 December. I previously I attended a two-day workshop of a positive organization. The information was provided considering every angle. In fact, when a dietician was talking about nutrition and was talking about meat, milk and eggs. When I said, "I am vegan". Dietician could provide no explanation in that regard. Other than that, it was nice."

**İÇB:** "Sexual health education is not given in any way. There is no such thing. Even in college, sexuality is not spoken. Persons who have never received any sexual health education and know male-female sexuality through myths are currently teaching. A promotional stand set up at the faculty once. It is as if the virus is spreading from that stand. They were passing by nervously. Even when persons are exposed to that image, they feel contaminated. This is a prejudice that cannot be broken. Televisions must announce for days that there is a cure. Only they can believe so. They do not even investigate themselves. Universities also have difficulties at some point in studies, but HIV is always seen as something that is not necessary. HIV-positive persons cannot even say that they are discriminated. That is why they think we are not discriminated. I do not think anybody follows an HIV association. They only know from the Internet. Even I became acquainted with HIV when I met someone living with HIV. That evening I went and searched the internet. They did not show me anything. However, I was curious and learned. How can sexually transmitted infections be discussed if we cannot talk about sexuality? As a country, we are still talking that what women can do or not professionally. Even healthcare staff do not know what HIV is. Even the doctor does not know. I received training on the subject when I was undergraduate. I attended a training held by a club at my own school. It was a short one. I also attended a workshop of a positive association."

As can be seen in the example above, it is necessary to make the policies produced fully HIV inclusive. Otherwise, inclusive and non-intersectional policies may exclude vegans, for example, as well as exclude other life practices, political views, preferences and existences. There-

fore, HIV policies to be carried out should be shaped in line with the needs of the subjects.

While the curriculum fails to provide the updated information on HIV and the experiences of those living with HIV, it reiterates the same mistake by providing a cissexist and heterosexist education system. In this system, LGBTI+ persons are ignored again and again. This education improperly provided on STIs can also be LGBTI+ exclusionary.

**İDE:** *"I was also open in the last phase of school. I also wrote on HIV while writing my undergraduate thesis. I was open at school and I come out by making a presentation on HIV in one lesson. At school, I was known. There used to be written in a book that "it infects more quickly from animals and homosexuals". This is HIV knowledge in the curriculum, although this is no longer the case. Persons are now accessing social media. I remember HIV from the TV from Savaş Ay and Uğur Dündar. It was the first time I heard about it. It was TV and newspaper back then; now the internet. Persons know what is provided in the headline. There are events where medical students distribute condoms on December 1st. They cling on it as if it was a great activism. Nor are they principled enough to be consistent. These studies and their contents change every year. I can say they are talking about this. Condom issue is a matter of cost; on the economic side, regarding class. If PeP and PReP are not accessible now, the reason is somewhat positive organizations. I cannot say that it would not have happened if the civil society had spoken about it, but it will take less rather than 15 years for this issue to come. It is patriarchal reflex not to talk about sexuality. All my doctors and healthcare staff colleagues I spoke with do not know HIV. A colleague was quivered with rage after coming from school and explained that this: while they were learning to use syringe, the teacher had said that the tubes of those who came for the HIV test are yellow or purple and when they see it they have a right to press the needle more. Sometimes I think that if they do not teach what we want, they should not teach anything. I attended training before. It was bad. A bad example was given. The last minute was an empowering, but dramatic things were said throughout the example. PReP and PeP have recently contained on the agenda of civil society."*

It is noteworthy that the participants have the same opinion regarding trainings and education. This consensus highlights how inadequate HIV is addressed in education. Today, while non-governmental organ-

izations take the responsibility for providing information on HIV, it is mostly those living with HIV who benefit from this information. While those living with HIV are more knowledgeable about HIV than other segments of the society by being the subject of the issue, it is problematic how other segments of the society can access updated information from right sources.

## 7.4. Experiences of persons living with HIV in accessing social services and civil society

Appropriate social service counseling facilitates the lives of persons living with HIV and empowers them against discrimination. Thanks to the right counseling and guidance, those living with HIV can go through their routine processes more easily and progress in peace in their processes. For this reason, social workers should have a map that covers those living with HIV, that is aware of the problems of those living with HIV, and can provide right guidance and counseling in the face of these problems. In order to protect and strengthen the human rights of the person when necessary; social workers must be competent to coordinate and follow cases with lawyers, professionals of psychosocial health, non-governmental organizations and, most importantly, national human rights mechanisms. Participants shared the following experiences on their social service experiences. In addition, their experiences with peer counselors and professionals of psychosocial health are included in this study in order to enlighten the researchers.

**KAQ:** “Once, I had a consultancy process. I went to an HIV organization once and had a bad experience. I went to them to ask for medicine but they told me that I was too late and that I should come tomorrow. I could not go there tomorrow. I came back crying. I had come a long way, and that is when I found someone on the Internet and asked for their help to find medicine I could not buy. They helped to find me medicine and so other persons helped me. The person newly diagnosed comes to you not by telling “Teach me”, rather by telling “Help me” and you should not say “come tomorrow”. In another counseling experience, there was someone who was a little older and that made me feel very comfortable. This person told me not to be afraid and that my life could go on as before. I told about my fear of death they comforted me.”

Those living with HIV want to hear not only professional information but also that their situation is understandable and that the solution is easily accessible. One of the biggest mistakes made in the counseling process is to treat the HIV process as a procedure that should only be followed and ignore the psychological state of the counselees.

**IAO:** “When I found out that I am living with HIV, I went directly to a psychologist. I could not connect with my first two psychologists. They did not provide me with the comfort and awareness I was in need. I have been seeing my school psychologist for two and a half years. I was diagnosed with major depression caused by anxiety. I was depressed for 4-5 months because I was thinking about my future labour life and I became depressed due to the fear of being unemployed. It is not about homosexuality but I have had a lot of anxiety about HIV.”

**KEK:** “Eight months after my diagnosis, I attended the training of a positive association on 1 December. It was good. I have been in contact with consultants and they have helped me a lot. I have seen there are still things I have not been able to overcome. After that day, I learned that I had the right to change my medication. They changed my life. I do not even remember living with HIV right now. I do not even think of it during the day.”

**AAA:** “Once I got social service from a municipality, then I got nothing apart from it. An old friend of mine also had a lot of support.”

**IEY:** “When I was unemployed, I went to the association and said I want to work as a volunteer in the association. They are so glad. I went to their meetings, met other persons. It was really like in the e-mailing groups, I thought everyone was cute. They had included HIV in their daily lives. I thought “Well, why cannot I be like this, why cannot I normalize? I went through stages at regular intervals such as acceptance and rejection. There was a secretary at the association and was leaving. I was already doing business with great pleasure. I wiped the tables and move the furniture. There are persons newly diagnosed, I tell them, “do not be afraid, nothing will happen”. Everything was hidden and you could not ask anything, but you could tell by the trembling of the voices and you wanted to hug. Then the secretary left. “we are going to post a job. You have been coming voluntarily for a year. Do you want a job like this?” Project Coordinator asked me. I wanted of course. Somehow, I was employed

*in civil society without knowing what civil society is and what it is not. Meanwhile, I started making the first contact with friends who were diagnosed. Nobody said, "You will do this". I shared it as I feel like it. They said, "You are fine on the phone. Do you want to do it face to face?" I panicked a little so that I could not do it, but I talked to other persons and got some prior information. Then I started working as a secretary and in peer counseling together. I started to be informed about the board of directors slowly. Now I normalized HIV so much that I was participating in any conversation. I was equipped now. Being diagnosed with HIV has really had a positive impact on my life. If I had not been diagnosed, civil society would have been just village associations for me and I would have been exploited in the private sector. My bad times helped me to build myself. I have accepted my missions. Once, I got counseling for social service. It was nice. It was effective. It was also peer counseling. It helped me a lot".*

Social service or peer counseling services provided by civil society are important for reaching volunteers and professional persons and dissemination of HIV knowledge based on human rights. Civil society should always be open to persons who want to volunteer in the field. However, organizations should measure the quality and success of consulting services, develop standards for this, and should provide persons in these positions with structured orientation training.

**IDI:** *"When I was first diagnosed, I went to a positive association. There was an older person who told me about the situation before and gave me advice. It was good too. I was diagnosed with HIV and I was very worn out. For months I put the blame on sex and realized that there was a moral understanding inside me that I could not overcome. I have not had sex for months. One evening we are sitting with a friend. Then one sexual partner called me. My friend knows it too. I never wanted to lose contact with that partner. My friend told me to go but I said "No, I cannot go". My friend said "You have to start seeing some and have sex at some point, you should not be prudish right now" and I went that day. I was relieved a bit. Something strange happened to me. If I did not see sexual partners 5 days a week, saw them for 2 days, if I was CD that day, I would have sex with 8 persons. It was hurting. Then I started having nightmares. These events happened within a year. Something has always happened in my nightmares: My medicines are always right in front of me in my room, a thief enters my house and steals my medica-*

*tion. I always had the same dream, I always begged that person to leave my medication. And my friend, who noticed this anxiety situation, said, "you are not okay, I will send you to my friend. I cannot deal with you since it is not ethical". Then my friend sent me to a doctor. The doctor was working with HIV positive LGBTI+ persons. I went there the doctor was so anti-phobic and asked "Shall I address you by the name on ID or by the name you are using? Teach me, tell me about my mistakes." I got psychotherapy for a year. We realized that the problem is because I have controlled everything and for the first time there is something out of my control and I hate it. The doctor offered to meet me one last time. By the way, I ran out of medicine and I stopped and did not take it again. The doctor said something very nice: "If you were the old you, you would not have cut that medicine on your own. So you are fine now. Lets graduate you from this". Since then I have no problem."*

**IKH:** *"I did not receive any social service counseling either. I received more peer counseling. I shared my experience and chose to learn like that. The places where I could get this were places where I could be open directly. When I wrote to an organization, they asked me for information to join their group, but that information is very critical. Giving that information is precarious. I am not an unknown person either. I am in the movement."*

**IAE:** *"I have not get any counseling from social workers. I hot peer counseling and thanks to them, I got through the process easily. Peer counseling functions as psychological support."*

Social service with a good knowledge of updated information, civil society with a good knowledge of updated information and psychologists with a good knowledge of updated information are significant. It is necessary to deepen these areas regarding HIV, where intensive studies have been carried out since the eighties, to adapt their approaches to human rights principles, eliminate discriminatory professional practices, produce knowledge on HIV, and provide expert support.

## 8. | Social aspect of HIV

### 8.1. Community perception

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HIV has meant more than one thing to society since the eighties. While the first cases of gay men in America in the eighties were initially described as “gay cancer”, the society still multiply the hatred towards sex workers such as “Russian disease” and “sex worker disease” with LGBTI+ phobic and racist views. On the other hand, in the West, HIV has been seen as a magazine tool since the eighties and has been introduced as a so-called “scandalous” headline. The same situation has spread to Turkey and the media in nineties has developed phobic attitudes by linking HIV with transgender persons and gays. On 3 November 1985, for Murtaza Elgin, one of the first HIV cases in Turkey, Hurriyet newspaper provided the headline on its news as “the first victim of AIDS in Turkey, a close friend of many celebrities in high society”. Again on 7 November 1985, on a news published on Hürriyet newspaper the headline was “And the hopeless escape is over in the AIDS ward”.

By being used as a means of intimidation, HIV has also been used as a reinforcement tool if what is considered is not “white” or “acceptable” is not scary enough in itself. For example, HIV is still attributed to immigrants, drug users, alcohol users and homeless persons. HIV has historically been identified with the ghetto. It is believed that HIV is found in socializing places such as cinemas and bars, which LGBTI+ persons frequently use. The myth that those who use those spaces, namely LGBTI+ persons, alcohol users, sex workers deliberately and willingly leave HIV-bearing materials behind these places, are reproduced.

In fact, it is quite possible to say that HIV is used as a means of aligning, intimidating, externalizing the problem and justifying discrimination. With the strengthening of the internet life, these discourses were transferred to the social media environments and HIV continued to be used as a means of intimidation and discrimination. For example, the

myth that Americans or Jews mixed HIV into cola to infect everyone is spreading with mass messages among the society. This situation is ultimately used to push the part of society deemed worthy to a ghetto into more ghettos, to purify the “white” ones, to keep sterile and bourgeois life sterile and bourgeois, and to increase the resilience of cis-heterosexual domination. However, in fact HIV, the “Human” Immunodeficiency Virus, concerns everyone equally. Raising awareness on HIV, protecting persons living with HIV against discrimination, combatting social prejudices, increasing the dissemination of right information is not only an obligation of states but also a responsibility that persons from all segments should take on their own.

When we asked the participants about their opinions on the place of HIV in public perception, they expressed the following statements:

**KAА:** *I saw what might happen in the discussions on social media. The persons we wanted to express ourselves were not the society itself. They were persons we could find responsive, and we were violated by them. When I asked for financial aid for an event from an institution that I thought they are responsive, they said “You are very fond of Russians. You should give the money” for example. Something like this. For example, there is no MP in the parliament speaking about HIV. All of this gives us enough data about society, but medical advances are progressing and promising. There is now the Covid-19 epidemic, and all countries of the world have produced science about it because it was a crisis. The information produced on HIV is produced as a special area of interest. Nobody says “Lets do something about HIV” in Turkey. HIV is not taken into account as much as the attention given to Covid-19. The state only provides aid. I do not want help. I want a solution. For example, why is not there a study on vaccination? Why do not they bring together scientists who want to work on HIV? Because it is a sexually transmitted virus and that is why they do not want to produce anything about it. However, they are struggling with Covid-19 intensely, this should be done about HIV. When the government covers my medicine, it provides treatment for me. This is not a production. If I buy condoms with money which the government does not distribute, it is not the government’s aid. There is a problem here if I am learning sexual health education at university rather than primary school. Meanwhile, I find the issue of anonymous HIV centers very important. I have heard that there are centers, which are closed, and these issues need to be followed up. I think the counseling capacities of HIV centers also need to be strengthened.”*

Anonymous test centers are centers where persons in certain cities can go and get tested with their nicknames without presenting their ID information. The anonymous testing centers in Turkey can be closed today, their field of work are blocked. As the number of these centers, supported by the Ministry of Health and opened by municipalities, increase, the opportunity for diagnosis and treatment increases.

**IAO:** “We are classified as dangerous according to the society. There are myths like the needles in the movie theatres, like the rumors on transgender sex workers taking money from pharmaceutical companies to spread HIV. Persons stuck in these perceptions. Perhaps because there is no visible HIV positive identity in society at the moment, it is also difficult for them to learn the right information. Social media news can be clicked, but I think those myths can be broken with the role models in Turkey. They need to meet more of them and see. Since there is no such person, they still have not met it. They still have Freddie Mercury and his death. The community did not encounter HIV-positive role model who is living healthily. It should not have been like this. While you are giving your blood, it can be understood from the tube colors what you give your blood for. I just need to talk to the doctor about this and the doctor just uploads the data into the system. Some reports are uploaded by the employees in the report room. I do not know about how that employee is responsive. Doctors may be a little better since they are sworn and they can lose their job. Because of these sanctions, I trust them, but I see it as if what the healthcare staff is doing can be easily covered up. I am talking about intermediate workers, not nurses. I do not trust their state of consciousness. Or, for example, it should be explained that why the documents signed in companies can be shared with third parties. What are the required situations, who are the third parties, what information cannot be shared absolutely? These need to be explained. In the category of dangerous workplaces, HIV test can be requested because of the occupational safety which is in the dangerous category, but this information should only be known by the doctor of the institution in order to provide the necessary service in such a situation, but if the institution learns this information in advance, it will not hire the employees. So this is something that should only be shared with the doctor. When a test is done, it must be said what will happen in that test. If there are no dangerous conditions, no HIV test should be requested.”

**KEK:** “For society, HIV is a scary disease of homosexuals. They think persons' lives are turned upside down. What it is encountered by the world in eighties, nineties are experienced in the moment we are living in Turkey. We live more normally because the drugs are more effective and there is almost no death, but the same discrimination and phobia continues. This will probably change after 30 years. I think there will be a cure for HIV in five to ten years. So perception may not even need to change. Other than that, we just have to explain it to the persons. Some things change when you speak. When I speak about it this affects one or two persons, but when the states speak about it this will affect many persons. That is why the states need to take the responsibility.”

Although HIV treatment is advanced, those living with HIV cannot come out and cannot talk about their problems or experiences due to the prejudices against HIV. With the combination of this problem with inadequacies in education and the fact that government policies do not focus on HIV, the rate of change in the perception on HIV in society decreases. Creating safe environments where persons living with HIV can come out, protecting them from discrimination through legislation and policies and increasing the spread of right HIV information are important in terms of the compliance of society's response to HIV with human rights principles.

**AAA:** “The periods can be divided into two as before the movie “Fig Jam” and after that movie. Before Fig Jam, it was thought that it was a disease spread by drug addicts and sex workers, but after Fig Jam, it was romanticized and considered with misinformation. Discrimination is obvious in both periods. There is a sentence for example “Merve with HIV going regularly to festivals” used a lot to make fun in the social media. This is the perspective of this society. In my own country, there is the understanding that if you are infected with HIV, you will die. There is a sense of fear. If I go to my family and say “I am HIV positive”, they will think that I will die or that I am a sex worker. There is no HIV anyway, in my country it is called as “Spit”. I think the perception can be a little better than the current one in 5-10 years. Corona may provide an advantage in this matter. The whole world encountered a virus and I hope it has positive aspects over HIV. New treatment methods will also reduce the phobia a little when it reaches more persons.”

HIV is also used today as a tool of degradation. As mentioned above, this degradation often targets LGBTI+ persons, drug users, alcohol users even those who go to the festivals, that is, those who have fun and perhaps have an active sexual life.

**İEY:** "Associations established as self-organizations by the patients started to change things. The media do not say "AIDS" anymore, but "person with HIV" and associations intervene in the media as much as they can. If you ask about HIV in the grocery store in the neighborhood, he will say "So-and-so died because of it". It is not the issue of him anyway. HIV is now more spoken and is becoming more of a target. There is no transformation as we want, but it is getting better, because the numbers are also increasing. Persons hear and see from their circles. If I look at it positively, we are one of the few countries good in terms of health and treatment, because our numbers are relatively low compared to those countries. Currently, there are around 24,000 persons living with HIV and the state does not take into account as a problem. This will not happen if the increase of numbers cannot be stopped. In Iran, the clergies are saying "Do not discriminate against HIV". Religious representatives have a big effect on the perception. For example, if Diyanet has had stated "Every trouble comes from Allah. O brothers, this is a disease. Do not discriminate", the reactions might have been different. As the numbers increase, there is a possibility of the state to impose older generation combinations. The most important thing the state has to do is to allocate budget to HIV as much as it allocates everywhere. The PReP treatment is not on Turkey's agenda. The state thinks "Why should I pay them for these persons to make love more easily?" To initiate PReP treatment for the LGBTI+ community needs lower budget than covering the cost of medication of HIV-positive person from the age of 20 until the age of 80."

**İDİ:** "I do not think it is like before. There were rumors that a transvestite fell from the apartment, the man filed a lawsuit against on homicidal attempt. There are no such things anymore. I am studying at university and I am close to the ones in class. They are younger than me, and I think Generation Z perceives life differently. They are not narrow minded, they are not outdated. I follow them on Instagram. Girls with headscarves, for example share the photo of Freddie Mercury. They do not like the perception of "we are closed with scarves and conservative".

*Everything flows positively. No matter how much the medieval darkness is attempted to impose on us, the society is getting positive. I do not know how it should be though. I am not very involved. "Do this, do that", I can not give you such an advice. I am not doing HIV activism. Therefore, I cannot say that this should be done, that should be done. God bless those who do, I can only say that the associations should increase their field of work more. On the other hand, I am afraid of something: I am wondering whether LGBTI+ organizations will increase the perception of gay cancer if they get too much into HIV activism. Therefore, associations, especially HIV associations, need to get stronger. They need to specialize in their fields."*

It is important for non-governmental organizations to address the HIV issue. Today, not only non-governmental organizations working in the field of HIV, but all rights-based non-governmental organizations need to speak out against the discrimination faced by persons living with HIV, to fight for the dissemination of updated and rights-based HIV information, and to update their policies in a way to include those living with HIV. Moreover, the field of HIV is one of the areas where the most discrimination is experienced but the least activity conducted.

**IKH:** *"Society is frightened. This is the case for many things. You cannot access the right information. The criminalization has been overcome a bit. It is even a good thing, when a discourse that does not negate it is developed. Somehow then society normalizes it. I do not think there are such big prejudices. Persons need some knowledge. There should be a space. They cannot give everyone the right information. When the persons obtain the right information, they will overcome the HIV issue. This is also the case with the LGBTI+ issue. There is an attempt to turn the personal concerns of persons into a social fear, but of course it does not go on like this. Nothing done today is in vain. I am hopeful. While a few persons worked for this in the nineties, now there are lots of persons who do this activism. Now we can say this is not only for medicine but also for my sexuality. In this turmoil, we turned to ourselves, we transformed persons and sometimes we fight, and this is not in vain. We unite by considering the inseparable nature. It is like the merging of bar associations with LGBTI+ movement. And when persons whose words are found untrustworthy vilify us, persons also become suspicious. Persons are transforming without realizing this transformation."*

**İAE:** "HIV is still a myth for the society. This is still somewhere. For the society, it is a heretical disease but far away in the unknown lands. It is like an epic for society but different in every segment. For health workers in a medical place, for someone living in a village it is related to "going to a sex worker"; in cities it is related to being playboy. It is very variable. But it is a disease that is feared and thought not to come to us. Nothing will be much different from that. I am pessimistic, maybe, but we are moving with baby steps. Persons still live almost completely hidden. I see it as if it will always be like this."

**İÇB:** "Society still thinks we will get sick and die. If you are HIV positive, you either have been with a sex worker or you are a sex worker. Or you are male and your partner is also male. You are among the servants that our Prophet disliked. You should not be in their sight. They think there is no cure for this. This cannot be overcoming either. They regard it as if every person with us will be infected. No matter how much you tell it, they will not accept it because according to them this is a trouble sent by God to fags. In my opinion there will be a cure for HIV and its name will not even be remembered. There will be just a bystander apathy for persons who faced this for a period."

**İDE:** "Society sees HIV as something that leads to death and is criminal. It regards it together with crime, with immorality. The mechanisms that make these decisions are strong. If there is democratization some day, we will not encounter any problems. The state gives some rights to small groups. Such as not being dead for queers, medicine for those living with HIV, being able to go to the police when they are subjected to violence, for women. They can use these leverages. If they want, they will take those back".

Based on the interviews, it is possible to say that the widespread perception of HIV in the society is embellished with myths and prejudices, intertwined with discriminatory ideologies, and this situation makes the lives of persons living with HIV difficult. In order to change this perception, an HIV policy that centering persons living with HIV should be adopted, especially by states, the media and those who have the power to influence the public.

## 8.2. Family

Those living with HIV sometimes came out to their families or have to do so. When this is the case, the reaction of the family may differ from person to person and from period to period. Since assigned or chosen families have a say in persons' lives, the attitude of families towards HIV-positive persons is important. Particularly for HIV+ LGBTI+ persons, the response of families can get even more complicated. The family's support and inclusiveness for subjects can protect persons living with HIV against discrimination, empower them and sometimes even save their lives. Participants stated the following about the family and coming out to the family:

**KAA:** *"In my family life, I came out to my mother at an early age. She guesses about my relationships, but in our home these issues are always ignored. Both my identity and my HIV status. My family knows my status indirectly. I told them that I had a blood disorder, so I would not be join the military and that I needed medication."*

**KEK:** *"My LGBTI+ identity is just something I struggle with my mother regularly. These issues have never been discussed with other family members, but they heard it, they saw it somehow. My mother has a habit of talking, arguing, and covering it up since high school. I guess that is the way she struggles."*

**IAO:** *"While I was out with my friends, my mother found my medicine and called me. She said anxiously that I should come home. I could tell from her tone of voice that she had cried. When I asked, "Did you find something? She replied yes. I talked with my brother before coming out to my mom and dad. I came out to my brother as gay and shared my HIV status with me. He did not know what to do and suggested to bury the matter due to my father's blood pressure problem. I did not want something like that. My mom and dad were crying when we got home. I told them first that I am gay and had unprotected relation. Then I explained that HIV is no longer killing so they should not be afraid. My father did not care about my HIV status. He had a problem about my homosexuality and that was the most upsetting point for me. "Will you continue to be like this?" he asked. However, this is what I am, I live this way, I came into existence like this. It was very difficult to explain this. I still do not think he understood it. Although he thinks that homosexuality is not a choice"*

*but an existence, he still thinks that I prefer this with my actions. He asked me "Are you going to keep poisoning persons?" and it really upset me. After a while, I started checking both my parents' browser histories. I was doing this to confirm if they reached the right information. Let's say they searched for thirty pages at all; twenty-seven of them were about homosexuality and three were HIV-related. Seeing this made me very sad.*

Families should once again reflect on their attitudes towards LGBTI+ family members living with HIV. Associating HIV with SOGIESC and the thought that LGBTI+ persons is the cause of HIV makes life difficult for persons. Attitudes and behaviors such as denial, rejection, and insult harm the subjects and be distanced in their relationships. The problems can even escalate and the domestic violence can be the case. The state should raise awareness of persons regarding HIV, LGBTI+ and human rights issues by developing social campaigns and lifelong training opportunities targeting the family.

**AAA:** *"I only shared my sexual identity to my mother. She does not know my status. Nobody else knows anything about me."*

**IYEY:** *"I came out to my mother. At the end of the high school, she saw Kaos GL magazines. "Why are you reading these?" when she asked, I said it is interesting "How are you interested?" she asked. Then when I came out as HIV+, we were able to talk about everything comfortably. My mother is a retired nurse. She said while taking blood, she had been very anxious and very upset and been a little harsh against HIV+ persons by think that they deserved such treatment as a punishment. She said "I mistreated them. Therefore this happened to you". We always got over such concerns by talking. She now reminds me to take my medications on time, for example."*

**IDI:** *"My family learned about the HIV issue themselves. They told each other. I told my sister when I found out. She took me to the beach with my uncle. At that time, I was having a phone call with someone. My sister was also on the phone and the whole family had heard all of it. We are a crowded family. In two days, the whole family learned about HIV, before I was able to do the HIV activism at home. They learned and cried, I have never encountered a phobia. I grew up in a conservative family. Conservatism has a comfort side regarding me. They are already*

*aware that this is a disease which is sexually transmitted and think it is a sin. I think they became sure that I am queer this way. I never encountered phobia because they did not want to face with me.”*

**İKH:** “*I am not open in my family at all. I take the advantage of being away and having different lives from each other. If we lived in the same house, I would feel the need to come out. Every day, for example, I cannot take medicine secretly.”*

**İDE:** “*I told my sister directly. I said after the first hospital. And I am open to my mother. There were too long processes related to my ex-partner. My address record was showing my parents' house and when I was in my home, the court paper were sent to that house, I told her from the very beginning. Then I saw her doing research on HIV. In the browser history I saw that she was looking the right information. That is why I did not interfere.”*

**İCB:** “*I was with my family when I reacted to the drug. I was sick and my mother called my sister because of my situation. My sister asked if there was any medicine I used. My mother opened my drawers and found my medicines and sent the photos of them to my sister. My sister learned that the drug is HIV drug but slurred over as a kind of infection drug. Then one day, there was a conversation on TV where HIV and AIDS were discussed. My sister paid attention since she was familiar. The doctor there said that if its not treated it can turn into AIDS. My sister said all of these. She had thought, “This child is dealing with these and cannot tell us. Why did we make him feel so insecure?” she blamed herself. By the way, my family is conservative but she still thinks so. One day she called me crying and said, “I know you are not okay. I am not feeling well, I want to come to you”. She came and wanted to see my doctor, and I took her to my doctor. Thanks to my doctor, who explained it very well, my sister got relieved. Then she returned back. Our relationship was normal afterwards. I have always been distant to my family. I do not feel good because my sister learned about this. On the contrary, I feel very uncomfortable. I feel like my privacy is violated.”*

The privacy of those living with HIV can be violated by family members, as also stated by the participants. Families should respect persons' privacy. Third parties should never share specific information such as health status of individuals with family members without their consent.

Coming out is something the persons may not or may desire to do when they feel ready at right place at the right time. At this point, what is necessary is to establish the appropriate grounds free from prejudice and violence, on which all persons can come out, in the family. States are obliged to protect LGBTI+ persons living with HIV from domestic violence on account of their health status and SOGIESC.

### **8.3. Friends**

In the context of participation in social life and freedom of expression, it is of great importance that persons living with HIV can come out to their friends. As it can be said each chapter, it can be said here as well, the necessity of creating safe environments where LGBTI+ persons living with HIV can come out. Isolation of persons from their social environment on account of their HIV status or SOGIESC and violation of their rights to privacy can negatively affect persons' lives. LGBTI+ persons living with HIV are frequently exposed to bullying, hate speech and violence within their peer groups. In this respect, they should be empowered in order to ensure their full participation in social life by taking advantage of appropriate psychosocial techniques and law enforcement. Participants shared the following on their friendship experiences:

**KAA:** “My friends told me “You are not like the others. How do you get HIV?” Then I questioned “Who am I?”. In their minds I was a stereotype that does not have sex every day, which is far beyond the definition of a fag. Learning this upset me a lot.”

**IAO:** “My friends were very conscious regarding the situation. They all knew more or less what HIV was from somewhere. They told me that I should not feel sorry for this and that it will not kill me. It always thought that they were not very involved in the matter, however. At first, they made me very happy with this solidarity.”

**KEK:** “I was also subjected to a lot of discrimination among my friends. I explained my identity to persons I trust. I was social, I had a lot of friends and they became distant. That is why I have just a few friends at university. I have been living an introverted life for three or four years. At least I have not been subjected to any discrimination by my current friends. They were constantly supporting.”

**AAA:** "Many persons in my circle of friends know that I live with HIV. My roommate had disclosed me to persons before I told them. Those persons supported me. They provided consultancy. I have not faced any discrimination."

**IYE:** "I also routinely came out to my friends. My professional profession is civil society. Surely they knew. I was telling, it was being talked about in a way, while we are chatting."

**IDI:** "I trusted my friends to be activists. The persons around me are not kind of stupid. I have not encountered anything bad by any of them."

**İKH:** "Somehow I needed support while waiting for confirmation. Someone had to know. I told my friends there. There was a situation where they felt very sorry for me. Theirs mimics, gestures and behavior never made me feel bad. Then I always be open strategically. I came out to my friends whom I wanted to know it. No matter how long has passed, coming out is still as difficult as for me as the first day. It is not something to be overcome. Coming out is something that never ends. Being gay, for example, I do not come out to anyone as gay. I am living with this identity anyway and I will not have any difficulties if I come out, it is not the case for HIV. It is as hard as the first day because this is something about nothing is spoken1.

**İDE:** "I came out to my friends all together and I am comfortable because they are conscious. They did not mind anyway. I heard that two of my very close friends were concerned about this, but that lasted for a short period of time".

**İÇB:** "I have a very close friend. I called my friend first when I was diagnosed. My friend was a little scared too and asked what we should do. I explained my hospital process and my friend was always with me from the beginning to the end, took me to the hospital, to the association. My friend spent the night together with me in the hospital. It would have been very difficult for me without my friends. You need incredible spirituality in such a process. You are looking for the compassion of a person next to you. I heard that there was someone who committed suicide on the day that person was diagnosed. There is such a big stigma underneath that. Even if it has a cure, they do not want to live with it. There is a huge social stigmatization. That is terrible. Yet it is not different from any infectious disease."

One of the challenging aspects of being diagnosed with HIV can be isolation and exclusion from the immediate circles. In fact, persons worry about the coming out processes as well as the diagnosis and treatment processes. Any negative attitude they may see at this point may cause persons to isolate themselves or to be isolated by their circles. Persons diagnosed with HIV often need a peer counselor to learn and relax, and need their circle of friends to get support and empowerment. At this point, it is essential that family, friends and partners to create a safe environment for persons. The friends should understand that the information on HIV status and SOGIESC of persons about whom they learned is confidential and they should avoid sharing it with third parties without the person's consent.

## **8.4 Partners**

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Persons living with HIV do not have to share their status with their partners, contrary to what is supposed. Persons may be exposed to violence when they come out to their families and friends, or when they come out to their partners. Moreover, if the person has multi-partners, coming out to a group may increase the dimension of violence even more. The fact that HIV status does not have to be shared is not only due to the Undetectable = Untransmittable (U = U), that is, the HIV RNA count of the person becomes undetectable and the transmission feature disappears. HIV status is private, personal health information. Persons should declare their status whenever they want and when they are ready, without feeling the need for an obligation. To do this, an effective legislative-policy framework must protect them from discrimination. In fact, rather than expecting from the persons to constantly declare their health information, the individuals should take their own responsibilities to be protected against HIV and other infections. Individuals can use methods such as condoms, PReP (pre-contact prophylaxis) and PeP (post-exposure prophylaxis) to protect themselves from HIV in the context of sexual intercourse. States have an obligation to make these methods easily accessible to persons of all socioeconomic levels. States can cooperate with the private sector and civil society to promote the methods of protection.

Use of condoms in a relationship should be based on mutual decision and consent. The parties should not manipulate each other to use or not to use condoms. Relationship with or without a condom depends on the consensus of the persons. Considering the situation in which the HIV-positive person may not know their status, condom can be considered as a protection tool in relationships independent of HIV. In addition, condoms protect persons against other sexually transmitted diseases. In the light of human rights principles, it is not necessary to envision a sociopolitical level in which the individuals are not obliged to explain their HIV status, but rather a level that they will not be exposed to violence and discrimination. Avoiding sexual life or preventing persons from sexual practices due to HIV both hinders the use of human rights and is an unnecessary expectation.

Participants' statements regarding the experiences with their partners as follows:

**IAO:** *"I can give an example about partner issue. I had been getting closer with the person I had been with for about a month, so I was nervous. Realizing that I was nervous, he asked me what had happened. I also explained that I am living with HIV. He got up suddenly and got dressed. He asked how I had not shared this with him before we got closer. Then he went to the toilet for mouthwash. I think he was an obsessive person. So I told him that I could not trust someone who had been in my life for a month and that he should be aware of this and I left his house. And then he phoned me. We met again, talked and he apologized to me. I think he had reacted involuntarily because of his unconsciousness. No matter how much later he became conscious, he could not overcome his prejudices and in the end we broke up."*

**KAA:** *"I came out to my ex once. When he met with me a year later, he did not touch me because I told him about my status when I found out about my status after we broke up. Sometimes I like someone but I do not even approach him because I cannot explain this to him. I take it off my mind. I think I should say if I have a long-term partner rather than a sexual partner. I see it as an area of struggle. I cannot hide my medicine. It is on the table both at home and outside. I only keep it when my sexual partners arrive. This is my trauma. I think I can face violence. If someone asks me what kind of medicine it is, I can be panicked. But I do not want a lover where I have to hide my medicine box."*

Under any circumstances, it should not be forgotten that HIV still causes prejudices and persons living with HIV suffer various violation of rights and hate speech due to these prejudices. Because of this situation, those living with HIV are at risk and often feel obliged to hide their status.

**KEK:** *"I do not share with my partners. Is it a problem? It was discussed a lot, as if we had to. Sometimes I think, but my counts are quite normal and in relations, I am protected. I think why I should share it and therefore I did not share it with anyone."*

**AAA:** *"I know I do not have to tell my partners. In a serious relationship, I thought I should say it in terms of having a comfortable relationship myself. I came out to my ex-partner. It was a tense moment for me. Until then I did not care about anyone, but I was nervous because he cared. I was even shaking. "Okay" he said. "We will learn over time," he said, but it think this was the reason that we have no sexuality in the six-month relationship."*

Persons with HIV should also be free from internalized phobias, even if they say that they are free from prejudices or that HIV is not an issue for them. Persons living with HIV restrict themselves because of these phobias and prejudices that persons themselves are not aware of. They have to avoid sexual and romantic relationships.

**IEY:** *"By the way, I am open to all my partners. I prefer to say it generally. Rarely I have felt something and it rarely happens to me. I mentioned it in our first conversation, I came out. He was upset and I tried to explain him what exactly this is. I tried to provide information. So I never got a negative reaction when I came out. Our relationship ended a year ago but we broke up due to another reason, but he updated himself well on HIV. I feel like I gained an extra sympathy for my honesty. I assume there is such a bonus. Even if persons are nervous and do not want to have sex, they are very polite. Of course there is a possibility that they may be dish on me."*

At this point, it is necessary to say that it is quite possible to get rid of prejudices about HIV. For this, persons should face their prejudices, understand the human rights problems of persons living with HIV, listen to their criticism and change themselves in this sense. Apology and self-criticism fundamentally empowers both relationships and those living with HIV.

**IAE:** “There was a man I met with. When I was newly diagnosed, I was feeling extremely bad and he forced me to explain. When he forced me, I shared my status. “How so, what will happen then, I already kissed you, has it transmitted to me now” he said. Rather than soothing, he just messed me up. He was someone who had relations with my circle of friends. I got paranoid if he can tell everyone. Indeed, he had disclosed me to a person. It probably spread among others too. I became paranoid and I wrote a long article saying that I should not let this to rule me and shared it as Instagram story. The moment I did that, my shaking stopped and I was relieved. There were more good reactions. Congratulatory messages. Even the persons who would react negatively respected to my stance. From that moment on, everyone tried to understand.”

Persons' disclosure of their HIV status may have similar motivations to disclosing their SOGIESC. Although HIV is a health condition, it has become an identity. For this reason, persons can expect support when they declare their status. The violence they face instead of the support can drag persons into isolation. Moreover, the fact that persons explain their status is a matter of their own, and at this point, the aim should be focused on protecting the quality of life of the subjects.

**İÇB:** “I did not know what to do when I got the diagnosis. I can overcome my traumas by expressing them. I told the persons I was with. Whereas at some point that is not my bag. Some says “Thank you” but I had also partners who stopped to communicate as if they had never met me.”

**İDE:** “Generally, I was telling my partners before we have sex. I usually say it a little later to someone I feel it might be long lasting, because there is still time to get there. I am telling it because I want them to know that I was dealing politically. I also had fun for the ones lasting for short periods. I liked to fight this or test the waters. Then I flinched from the discussions on social media. I started not to express. I have been seeing someone for 4-5 months. I was worried when I came out due to the fact that this partner is a health worker, this person thanked me and it is over.”

**İKH:** “I used to express it because I was feeling guilty. I still get the risk of being insulted, but I am in a position to handle that as well. If they do not stop seeing me, my partners are already saying positive things. It was also happening that my conscious partners could not grasp U = U well.”

*For this reason, while condom was not important in their lives, if they ask for condoms I could feel it. Of course, they may want to use a condom. It is not a problem but obviously they do not consider my status that way. Nobody wants to be labeled as HIVphobic anymore, but they find a way.”*

In the case of U=U, persons do not have the ability to transmit, even in sexual relationship without condoms. This is scientific data. This information was obtained as a result of studies conducted on more than a thousand couples with a viral load of less than 200 where one of the couples is HIV negative. These couples are chosen from a variety of sexual orientation and gender identities. During these studies, this data was obtained after nearly 100 thousand sexual intercourse. There was no transmission from HIV positive person to HIV negative person in any of these 100 thousand participants. This scientific study<sup>3</sup> has also been accepted by the World Health Organization.

## 8.5. LGBTI+ organizations, HIV organizations and other NGOs

During the first serious spreads of HIV in America in the eighties, this spread first became visible within the LGBTI+ community. Among the reasons for this, it is possible to count the limited access of LGBTI+ persons to health and the condom being denigrated by the conservatives. The spread of HIV within the LGBTI+ community even led HIV to be described as “gay cancer” for the first time. LGBTI+ persons living with HIV and the LGBTI+ community are the ones who raised up voice against the inadequacy of HIV-related healthcare services, the lack of appropriate treatment for persons living with HIV, the lack of appropriate treatment and delays, the ill-treatment of persons living with HIV, and the monopolization of the pharmaceutical industry. From past to present, HIV is historically on the agenda of the LGBTI+ community. LGBTI+ organizations in Turkey have included the issue of HIV since the first times. Even if it is to be said that these efforts were carried out with limited opportunities and limited policies, it is essential that LGBTI+ organizations provide counseling and guidance services to LGBTI+ persons living with HIV.

<sup>3</sup> For more information: see. <https://i-base.info/htb/32308> and <https://i-base.info/htb/34604>

When it comes to HIV organizations, these organizations since the eighties in Turkey are visible. Even if we first saw that doctor-based HIV organizations focusing on "fighting" against HIV, it is possible to say that the subject-oriented approach has been strengthened since the 2000s. Nevertheless, considering the fact that HIV-related studies conducted in Turkey are related to the field of health since the nineties; it can be observed that they are insufficient regarding the rights of persons living with HIV and the policy centering the subjects. While it is essential for LGBTI+ organizations to develop their HIV policies and provide appropriate counseling, the same should be said for HIV organizations to develop LGBTI+ focused rights-based policies.

Although other non-governmental organizations do not show enough interest in HIV, there are those who make efforts in this regard. Especially youth organizations, women's organizations and rights-based organizations sometimes include HIV issue in their activities and studies. These efforts are also mostly health-based and it should be noted that there is a need to address the rights of persons living with HIV in a wider. Reminding that the participants of this research you are reading are HIV positive LGBTI+ persons, we can list the participants' opinions about LGBTI+ organizations, HIV organizations and other non-governmental organizations are as follows:

**KAA:** *"Positive organizations are very mechanical. I was that mechanical before I found out that I am living with HIV. I did not know that some of this would be traumatic. They also do this during the consultancy process. They are mechanical. The advice to be given about the steps to be taken is meaningless. I was screaming inside "help me overcome my fears". When I ran out of medicine, I could not see my friends because I thought that I was going to die with the flu. It is a little sad for me. I think many persons in the LGBTI+ movement are also afraid of HIV. About this, I saw persons telling, "Do not I have the right to be afraid?" There are such persons in my inner circle. LGBTI+ persons are a very traumatized population related to HIV, a community that is forced into isolation. I think those living with HIV who are heterosexual are not so isolated. So I think those in the HIV movement should engage in LGBTI+ inclusive activism. We are a group that is not recognized by the state and cannot benefit from social rights and we are dealing with HIV. In this sense, we should not be ignored. I do not find the consultancy capacities of organ-*

*izations sufficient in this sense. Besides HIV and LGBTI+ organizations, there is V-Peer that raises this issue. There is no other organization other than that. For example, feminist organizations do not address this issue."*

The counseling provided by the civil society is a process that requires experience and expertise. Experts should always approach their counselees with the same interest in these processes. When it comes to LGBTI+ persons living with HIV, the counseling process may need even more multi-layered approaches. As a matter of fact, even if LGBTI+ persons are not persons living with HIV, they are persons who are often associated with HIV. It is therefore essential for HIV organizations to transform themselves with a LGBTI+ inclusive manner. This is deeply related to the principle of non-discrimination and the pluralism principle of rights-based civil society.

**IAO:** *"I like the policy of LGBTI+ Organizations and HIV organizations. Everything done and the stance is very correct. I appreciate the news, the style of discourse, the way the news is given. I think there are a lot of persons who do not understand that stance. It is necessary to explain that stance first. Instead of having a direct stance, it is necessary to explain where the reaction comes from. First, it is necessary to teach the basics of mathematics, not the integral calculus. Persons who do not understand this stance may assign a different meaning to it, but I am satisfied with these in my own way. I think their consultancy capacity is also good. When I learned that I am living with HIV, I got peer counseling from the LGBTI+ organization in the city I was in and I was satisfied. During the employment process, I intend to seek consultancy from one of the positive organizations."*

**KEK:** *"I do not think LGBTI+ organizations have enough awareness about HIV. They try to get around to the issue with insufficient events that are held only on 1 December. This is a bit of the problem of individuals. There are HIVphobic LGBTI+ persons and organizations do not provide the necessary training for this issue. There are just a few organizations working with HIV associations and there are not apart from them. I contacted only one of HIV associations and we had good communication. After that I felt that I can get counseling if I want. They instilled this confidence, but the problems of positive associations among themselves bothered me. There are just three or five associations already, since they had disunited due to the conflict of interest, even in the trainings they were talking about that,*

*this bothered me. They do not build a struggle that organizations should do together. One or two activities organized by LGBTI+ organizations and HIV organizations together are actually the example of this, but these activities do not continue. I also stopped following the events. I do not find them enough. I do not know, actually I wonder if HIV organizations do not feel themselves close to LGBTI+ organizations. I do not find their consultancy capacities sufficient. I once called an LGBTI+ organization and learned that they do not work in the evening. When I called the day after that for three or four times but could not reach them. I have not heard that other non-governmental organizations have an approach to this issue. It means no. If so, I would have heard about it. I do not think they are doing enough work. Maybe I do not know the field much. ”*

Considering both the historical and political proximity of LGBTI+ organizations to HIV issue, one of the claims of LGBTI+ persons living with HIV is that LGBTI+ and HIV organizations to cooperate. One of the main reasons for this is that the subjects realize that organizations working on both health status and LGBTI+ rights need to fight jointly with this different but intertwined human rights issue. Moreover, HIV organizations can mainstream LGBTI+ rights within their communities and vice versa. In cooperation with these organizations, persons think that they will be able to be represented more and that the multiple discrimination practices due to being HIV positive and LGBTI+ can be prevented more effectively. This is seen not just as an opinion but a strong desire and a just claim.

**AAA:** “*There is support from a few LGBTI+ organizations now, but there is no intensive work done. HIV organizations are places that work systematically. That is why I do not feel good. They did not make me stronger. I do not think they are empowering other individuals. Only one organization supported me a lot. I have been thinking about until today that LGBTI+ associations are doing nothing with HIV associations in order not to appear to support some myths. What some LGBTI+ organizations have done recently is relatively good compared to others. HIV associations do not want to be mentioned with together LGBTI+ for the same reason. Some HIV organizations provide only counseling, not peer counseling. This is a bad thing, because we want to talk to a peer, to be in solidarity. I have never seen other non-governmental organizations in this area. Something I have not come across. I see only one cooperative doing something in this area on 1 December”.*

LGBTI+ organizations and HIV organizations do not cooperate as expected, leading to the opinion among the participants that LGBTI+ organizations do not want to be mentioned together with HIV or HIV organizations do not want to be associated with LGBTI+. This situation causes the participants not to feel close to LGBTI+ organizations and HIV organizations, given that they are the subjects of both issues.

**IEY:** “In past, some LGBTI+ organizations had a policy that “It is not our problem too much, let’s stay away”. A LGBTI+ organization must provide informative articles on HIV on its website. Nowadays they want to do something in the HIV field, even though they did not share their status with their community. Perception is breaking down now. This is, yes, everyone’s issue. I fought a lot regarding this in HIV organizations. Well, you are having a meeting and if thirty persons are coming, twenty-six of them are LGBTI+ persons. If you serve this community, you should. HIV organizations still have a goal not to be seen as a LGBTI+ organization. It does not matter what your name is. That is why it is necessary to remove the defense mechanisms. I think the counseling capacities of LGBTI+ organizations are good. HIV associations are also doing well. There are some minor problems. HIV associations only have a problem of professionalizing everything, but peer counseling is also very important. Persons want to listen from someone like them. Women’s associations especially want to be updated in the field of HIV. Human rights organizations are the same.”

Peer counseling is of great importance in the HIV issue. Persons living with HIV may even think that this is a fatal condition when they are diagnosed. For this reason, peer counseling is critical for the persons diagnosed with HIV to see someone who is healthy and psychologically strong and to be guided via the experiences of other persons diagnosed.

**IDI:** “It is positive in terms of LGBTI+ organizations. Let me tell this first. Previously, organizations were working on this issue. They still work. I think it is getting better and better. It is bit about that: there used to be no such thing as a HIV activist. I did not know them. The persons I saw for the first time in that regard are just you. Sometimes I get angry, not about the organizations, but about the queers themselves. This is another matter, but I say, I am glad I am an activist and I am glad that I know these persons. Sometimes I fall in love with this movement, because we are organizing. I have been social media user for ten years but I have

never seen another movement than this movement in Turkey which put aside their internal discussions on such a matter, but try to fight the “enemies” altogether. We are fighting well with TERFs right now. “I do not have to tell my status, you should use condom” said the courageous queers. I do not know HIV organizations well. We also see how shady<sup>4</sup> the HIV organizations can be. I do not know how good HIV organizations are regarding counseling. My friend had called a positive association for me. I was able to make an appointment with them. I also know that they provide drug support to those who lack medication. LGBTI+ organizations are a bit insufficient in that regard; it is not just the case for the field of HIV. They also are insufficient in other counseling services. Frankly, I have no idea what other organizations are doing.”

**İKH:** “I am not very interested in positive organizations. They already provide counseling for HIV-negatives or provide counseling to those who are first diagnosed. I have overcome these processes already, but I have other demands. They do not advocate for the fields where they can show personal issues. It may also be because the work is progressing by funds. I guess there are some factors affecting them like their relations with the state. If you can still sit at that table, it means you have trump cards. They should also use these trump cards well. They can open up a space for themselves politically from here. Or you can include volunteers in the field. They behave like cis- and heterosexual. They are afraid of developing a discourse about LGBTI+ persons. They cannot develop a rights-based perspective. They think “The more we look cute, the more persons we can reach if do HIV activism in line with the expectations of government and funding agencies. However, this prevents LGBTI+ persons’ access to health. There is nothing to make social rights visible.”

“LGBTI+ organizations have such a stance that embrace this issue relatively more. We must accept this. LGBTI+ movement can say “The HIV issue is not just an issue for LGBTI+ persons” as well as “There are HIV positive LGBTI+ persons”. Organizations are therefore not HIVphobic. LGBTI+ organizations and activists update themselves by their nature. The moment they say “we do not have a phobia”, it is the problem. When you think of this, you are limiting yourself. If all LGB-

<sup>4</sup> TN. Throughout the document, *shady* (adj.), *throw or throwing shade* (v), *shade* (n) , *shade-thrower* (n) are the words chosen by the translator in order to refer to the words: “madileşme, madı, madilik/madilesmek” in lubunca (LGBTI+ slang). Although in some resources “madı” is translated with words such as madness, evil, bad; the translator prefers to use these lexical cognates having common etymological origin.

TI+ persons are to be addressed, then HIV + LGBTI+ persons should also be in it. We have to admit that the LGBTI+ issue is related to HIV. We should be able to say We are HIV positive, so what?". Mechanisms that protect HIV-positives are needed. The most informative posters are for HIV negatives. HIV-positive persons are not centralized. I find LGBTI+ organizations more sincere and successful on this issue. HIV organizations know that if they have an LGBTI+ issue with them, it is very difficult for them to approach the institutions. LGBTI+ organizations, on the contrary, are not concerned about approaching such. The counseling capacities of LGBTI+ organizations are very health-oriented. I do not know if they provide counseling on the social rights of HIV-positive persons because they are not working on it anyway. Of course, when you are not studying the intersectionality between HIV and LGBTI+, you do not have the knowledge about it. You should be providing details. They are not there yet. I do not know much about the counseling studies of positive associations. For example, they do not have proper studies regarding the law. They do not carry out studies that will strengthen the subjects to take legal steps. As far as I know that there is no one else working on this subject. HIV is not on their agenda. When even positive organizations consider this as a health issue, it is normal that human rights organizations may consider this as. While discourses were developed for the subjects against the same sermon, no discourse was developed for HIV-positive persons. This is not an issue to be considered just as health related. It is necessary to raise up voice about social rights. To what extent do the organizations for persons with disabilities have concern about the HIV positive persons with disabilities? Or I do not know if women's organizations are concerned. I hope they do. The discourses are not inclusive".

Subjects who have undergone the diagnostic process and continue their routine controls become curious about other processes after this stage. The subjects and stories of the subjects living with HIV maintain their uniqueness and form the basis of a new policy. In fact, the HIV activism in Turkey have been health related since the eighties but recently it has gradually changed its course because the subjects want their claims to be discussed in detail. When it comes to LGBTI+ persons living with HIV, the subjects first expect this from HIV organizations and LGBTI+ organizations. Considering the transforming policy, organizations' policy making by focusing on those living with HIV lags behind compared to

other studies. Organizations should pave the way for this to change on behalf of those living with HIV to develop policies.

**iÇB:** “I contacted a positive association before. Before that, I also contacted an LGBTI+ association. I asked them what I should do since I felt lonely. The person there said I should lower my voice, maybe the intention was good because there were others there. Then this person introduced me to social workers. Social workers said “search for a positive association at Google and get an appointment”. I can already do that. I came to share my feeling of loneliness. I sent an e-mail to a LGBTI+ association several times and could not receive any answer. I only communicated with one positive organization. The activism they do also make me feel better at some point. I think cisgenders should raise up voice on HIV. There is a perception in the community in Turkey that “This is a transvestite disease”, I think HIV-positive cisgender persons are more radical. They are doing their best about HIV. The organization I mentioned helped me a lot. They even returned to my calls at night. When I communicate with another positive organization, they said “We took the note and the specialists will contact you when they come”. They never called me back. There is some artificiality in associations. I saw it. There is no field study conducted. Will everyone write articles? I heard that associations abroad are better and provide therapy services. Or is not there a conscious peer counselor, who can provide guidance? They are superficial about HIV and turned a deaf ear. They must know how to approach when a HIV-positive person comes to them. It should not be as if their first time. They slur over and this make you feel bad. It makes you feel worthless.”

**İDE:** “LGBTI+ organizations seem a little more get used to this issue. HIV organizations cannot get used to LGBTI+ persons. I guess this is because of multiple discrimination. I feel not being included in HIV organizations. LGBTI+ persons’ getting used to it is a late one. They are getting used to this topic that has been on the agenda for 30 years, only this year. I think the policy making style of the movement has changed, but I think that the statement “We do not want to be associated with HIV positive ones” originated firstly from LGBTI+ organizations although there are claims on the quite the opposite. At least that was what I saw when I researched it. The reason was that the first policies of LGBTI+ organizations were made from a whiter, gay-centric perspective. Old policies shaped the current sexual health management. While the LGBTI+ move-

ment got over this, the HIV movement could not get over. Counseling should not be the only concern of an institution. If it is so, you open a counseling center. If you are an association, you have to make an inclusive policy. There is no capacity building on HIV in the hotlines of many LGBTI+ associations. They try to touch it, but the it is not on the agenda of other associations. They work on a rights basis, but it would take 10 years before we get to this side of the right"

The fact that LGBTI+ persons living with HIV cannot be organized is another issue. The subjects, unfortunately, cannot produce words within the movements that they think cannot find a place for themselves and do not include them. Considering that the participants have contacts in both movements, the issue of not being able to organize and not feeling belonging gets deeper for subjects who have never had contact with LGBTI+ organizations and HIV organizations or activism.

**IAE:** *"I am far from being organized. I cannot follow much, but I tried to participate in the 1 December activities. I find associations a bit insufficient. I think not only associations but also persons tend to ignore it. That is why I cannot blame the associations. HIV-positive individuals are also inactive. They cannot open themselves of course. This has become an invisibility cycle. It continues as something papered over. HIV is an issue marginalized in every environment. We have to establish solidarity among ourselves. I wanted to make such an initiative for a while, but somehow, the organizations and persons I communicated with on the HIV issue wanted to leave HIV in a private sphere. I often think about how we can create safer spaces and explain ourselves more. Some institutionalized associations are also disconnecting with persons. The first association I called told me "Have you not been diagnosed yet? Get a diagnosis, lets talk later". The institutional area is breaking the links. Positive organizations prefer not to mention LGBTI+ persons at all. They leave it in health dimension. Experiences should not be ignored. While the corona can be normalized and explained today, we have not been able to explain for 30 years by making it a taboo."*

Institutionalism can sometimes hinder the way of organization and policy making. Associations should have much effort into activism as well as organizational studies such as administration, counseling and organizing events. Today the political nature of LGBTI+ movement in Turkey is impressive, but it is not possible to say the same for the HIV movement.

On this ground, which has not been sufficiently effective in the political sense, it becomes difficult for subjects to come out and develop discourse.

## 8.6. Social exclusion and stigmatization

LGBTI+ persons living with HIV can be excluded and stigmatized by their families, friends and partners, as mentioned in previous chapters. This exclusion can also be encountered during the exercise of rights such as health, education, work, housing, and participation in public life. HIV-positive and LGBTI+ persons, separately or together, cannot find a place in the mainstream media to speak about themselves as subjects. On the contrary, the media remain indifferent to widespread human rights violations and hate speech or can play a role that further feeds prejudice and hatred. Persons may experience problems even in accessing goods and services. So is very difficult to talk about a HIV positive LGBTI+ subject who has not been subjected to an exclusion or stigmatization. Unfortunately, very few subjects can raise up their voices against this stigmatization and exclusion. Moreover, the system suppresses the voices of the subjects and build obstacles for them in enjoying their rights.

Within the scope of the study, the participants shared their experiences on social exclusion and stigmatization as follows:

**KAQ:** “However, I still felt that the medical staff were moving away from me. When I was diagnosed, my sexual orientation and gender identity were not asked. There was a doctor back then. The hospital was working on HIV. The doctor was a homophobic person while also conducts studies about HIV a lot, but he was homophobic. In the family I can feel that my mother was upset. My mother used to be upset when I was a child. It started when I learned that I was not a man when I was eighteen. When the neighbors said, “Now you will marry off your child” me and my mother just catch our eyes and we smile at each other, and she says, “No, my child will not marry”. But I do not know what kind of difficulty my family had in this regard while I was away. I do not know how they deal with these. I guess I let it go a little bit. As for me, I am a political queer. My partner choices are exhausting a lot. I do not share my status

*with my partners. I had not seen anyone for a long time. There are times when I still fear. At first, I believed I had to use condoms all the time. The persons in Turkey do not use condoms. I am one of them. I sometimes forget about it. When I found out that I am living with HIV, I was giving condoms to my partners as if it was my responsibility. This time, they have a reaction and ask, "is there something going on?" I am facing such a reaction. This question makes me to think that there really is a problem and it traumatizes me. I think the persons who are telling us "You will use condoms forcibly" do not have a sexual experience because there is no such practice in Turkey when it comes to the bed. It is far from reality. So now I offer it, most of the time they reject to use it and then I leave the condom aside."*

While LGBTI+ persons living with HIV are discriminated against due to their identities and status, the persons around them may also be discriminated in the same way. This is known as "HIV related stigma and discrimination" in the literature. When the persons around such as family members, friends, and partners interact with HIV-positive LGBTI+ subjects, their relation may become the target of hatred and discrimination. This situation shows us how powerful the system established to isolate HIV positive and LGBTI+ persons is.

**IAO:** *"When I first found out, the doctor asked me, "Are you infected as a result of homosexual relationship?" My own doctor asked the same question, and I think straight persons can be given PReP, the doctor asked me to find out in that regard. When my family found out, they were very upset. In the early days, towels were separated, toothbrushes were placed separately, my clothes were washed separately. They realized that over time it would be transmitted in certain ways. Now, I am having problems on account of my sexual orientation, not HIV. I think I raised the awareness of my friends well. They support me when I feel bad. I have never had a friend who discriminated me. As for the partner issue, I want to explain to my partners after a month or two of dating. I do not want to be in close relation until the disclosure process. I explain when I feel safe and our conversations end in less than two weeks. This has not happened to me once. I have experienced that four, five times."*

It is unnecessary to separate the towels and plates in order to be protected against HIV, which has a specific transmission route. Situations such as using common pool, common plate, common towel, mosquito

bites, cat scratches or social behaviors such as kissing, hugging, shaking hands do not cause HIV transmission. It is also out of question for HIV transmission; no such zoonosis transmission or human to animal transmission is possible. In addition, although HIV is transmitted through unprotected intercourse, transmission is not in question in unprotected intercourse of HIV-positive persons whose viral loads are at an undeterminable level. The probability of HIV transmission to baby is less than 0.5% with the procedures performed before, during and after pregnancy.

**KEK:** *"I did not experience any discrimination during the hospital process due to my LGBTI+ identity. I am not discriminated against because they see me and consider me to be a man. Regarding my friends, I wanted to tell my close friends a month or two before I was diagnosed. As soon as I said I have suspicious, I they told me "We hugged you, are we infected too?". I think this is the phobia. This situation hurt me. Apart from that, I did not experience this in job application or employment process. I have not experienced this in my family either because they do not know about it exactly. I think it can happen when they know. Because I know more or less how they react to the news on TV. They are not very understanding and conscious. When they asked me why I was using this drug, I said it is immunodeficient. They did not bother too much because they did not understand. Before I got the diagnosis, there were forums. Places where persons living with HIV talk and communicate. There I read suggestions for this disclosure problem, such as putting pills in vitamin C boxes. I thought of doing this but then gave up. I think I want my family to learn, but I do not have the courage to do it. I was not discriminated by my partners, but I guess I did discriminate one of my partners. My partner came out a person living with HIV and told me that I need to be tested, and a conversation started between us and with a momentary mistake, I said "Because of you..." The reason was that I blamed myself. I was not blaming my partner anyway. I also know that that partner infected me. We cannot know anyway. I tried very hard to lenify my partner. I was not discriminated against because I did not share my HIV status with other partners. My friends were very conscious. They learned a lot to support me, and they tried to teach other persons in their own lives. So they are exposed to the negative reactions by other persons: "Are you also positive why you are defending?" They got such reactions. When I first shared my HIV status between friends, "How can you get HIV, are you a sex worker?" they also asked.*

**AAA:** "During the times where I was sex positive, persons were saying, "You are making love so much, be careful, you will get AIDS". It was discriminated by my friends, but there were some issues due to their ignorance at first. Even if they did not say it from a phobic perspective, I could see that there was phobia in the background. A friend of mine said that I might be deported. When I told one of my ex-partners I am HIV positive and recommend my ex to get tested too. The test was negative. Then, when we spoke after this, my ex showed me photo of a latex outfit that completely covers the body and told me "I will wear this from now on". "This is hurtful, even though you know I have been diagnosed" I replied. Then my ex fixed their opinions. One of my ex attributed every problem in our life to my HIV-status, if something was going wrong in our relationship. My ex would always expose me to the friends by saying "I love so much that I do not care about HIV status." but at the same time telling me "How could you do this to yourself?". There was mobbing. Even when leaving my ex said, "We are breaking up because you are HIV positive". I was thinking that nobody would love me so much. I really believed for a while that I would always be alone. One of the doctors thought that I am a sex worker when asking me questions about the diagnosis. "How many persons have you been with in a year?" They asked and I said "around 500". "You must be a sex worker" they replied and I said, "No, I am willing". And also some persons were asking "Are you sleeping with foreign nationals?".

Although sex workers, LGBTI+ persons and drug users are considered to be in the "key group", there is no special correlation with HIV. The assumption that the person is living with HIV due to being sex worker, being LGBTI+ or having relations with foreign nationals directly linked to LGBTI+ phobia, prejudice against sex workers and xenophobia.

**IYEY:** "Before HIV, I was not open to persons around due to my LGBTI+ identity. I used to go to the meetings of LGBTI+ organizations, but I was not open. It was obvious though, of course. There were just jokes, but I was not directly discriminated. When I started coming out, a friend of mine whom I loved very much said: "I love you very much. You are very sweet. You are very thoughtful. Be careful, there are a lot of diseases, be careful they get AIDS". I jolly my friend along and explained what HIV is. It was actually a way of showing love with ignorance and good will. I gave a speech on HIV in an HIV activity of an LGBTI+ organization. Then I came out as a HIV positive person there. It was after my routine presentation. The persons in the meeting room paralyzed, there was a

total silence. I came out for the first time in front of a community. They said "It is very valuable information thanks for sharing this with us." I felt more normal. Then we said "Lets do this occasionally". Then someone from there, who was also from my circle, asked persons "Did you have intercourse together? Are you protected?" trying to confirm it. This person had done something with good will but in an ignorant way without my consent and knowledge. Then that friend got the diagnosis years later and apologized to me. It is weird actually; When disclosing someone else, without having any test or without knowing themselves, it is weird. That is the answer to the question: "What is the reason behind the fact that there are no open activists living with HIV in LGBTI+ associations?" It takes a lot of time for persons to tell their family that they are positive. It used to be a gossip mechanism. Is there still? Yes, there is. Since I am open, I am not participate in this nowadays. In the past, the community could not create safe spaces. It is better now."

"I came out to a close friend and we lost contact. It is because of this friend, never called me and asked about me, already had a phobia. When I shared this person cried. When I explained I am healthy and there is nothing to worry about. "I will always love you, I will always call you" my friend replied but never came to our meetings with excuses. After a while, we lost our connection. I have also experienced discrimination by partners. Everything is very good, nice, but they always say that they cannot have sex with me because they are scared, cannot be nervous. They begged me to understand them, but they never threatened me. I am open, but there were times where I have been rejected. There was nobody who not know about my LG-BTI+ identity, even though they knew that I am HIV+. The straight persons I give peer counseling do not ask directly but ask questions like "Do you have a girlfriend? Do you think to get marry?" but my LG-BTI+ counselees can ask directly, "which pubs are you going to?" for example, by being so sure about me. There have been times that my circle of friends was afraid of being discriminated. For example, when I met a friend of mine once, my friend was concerned "they will think I am HIV-positive too, I am constantly with you." Of course, this person who said this is also HIV positive but a closed one whereas I am open. So because I am open, when they see another person besides an HIV positive, they can definitely label them as HIV+. When I shared it with my mother: "Did you sleep with strangers?" she asked. Also, I was very ignorant about HIV before. I used to go to common baths a lot to be with foreign tourists. That is why I thought to myself that I definitely got HIV from a stranger. I did this by myself."

**IAE:** “I am open and proud about my queer identity and HIV status. Therefore I did not experience such discrimination. I am not open to my family. They are extremely conservative. Also, if they learn, due to their paranoia they can try to make me to use folk remedies. I did not tell them. I mentioned it on Instagram. Somehow I am in a queer circle and persons tried to understand more. I did not get such a reaction like “How come will it be?” Rarely I have gotten ridiculous reactions from men following me, such as “From whom did you get it? It would be like this if you slept with everyone”. These were very few, of course. I have an environment made up of persons who are conscious about this issue. The first time I said this, the reactions like “Oh! What a pity! How will it be?” made me nervous. I find such reactions: “Are you okay, are you taking your medication?” discriminatory. As I said, my healthcare staff bothered me. They have no consciousness about it. I cannot understand how ignorant they can be although they are in the bloodletting and healthcare sector for such a long time. There are no expert persons anywhere though. When I told my partners before and asked them to be tested because I am HIV positive; one of them informed everyone about my HIV status in the workplace. One of the persons who learned my status in this way is my current long-term partner.”

Those living with HIV can be perceived as LGBTI+, while LGBTI+ persons can also be considered as HIV positive. This is one of the prejudiced behaviors that are frequently observed. When those living with HIV come out, pitying the subjects and showing this through behaviors are not empowering but rather weakening of resilience. For this reason, it will be a much more empowering approach to thank the subjects for sharing their HIV status and try to have awareness on HIV, LGBTI+ persons and human rights in the process.

**IDI:** “So I guess: my butch mood provides more protection. My doctor and the secretary know me. Nobody knows anything about this in the hospital. I am not visible like other girls. I provide a space for me to hide myself. Since I am a public officer, I cannot be so drag. However, I experienced this by one or two ignorant sexual partners. They are really swag lachos and are slightly ignorant because they are real tranny chasers. I scored them off, of course. They subjected me to HIV-related stigma for being transgender without knowing whether I am actually HIV positive.

*"I hesitate because I am HIV positive. I can be drag sometimes actually. Then after I found out that I am HIV-positive, I stopped. I did not want to be forced into sex work. I had a self phobia. I said myself "If this is found out, there is no other option for me apart from sex work" and therefore I stopped to be a drag. I do not think about gender reassignment right now. They cannot imagine if I am transgender from my appearance. My family probably thinks that I am gay. I am open to my nephew. My nephew said, "The moment the family found out about your HIV status, they became sure that you are a queer". I have a gay friend, a HIV positive. He is telling his partners. Gay relationships can be between more educated persons. There is no such thing in transgender persons. We actually have relations with cis heterosexuals. I have relations with men who are tranny chasers. This is another universe. That is why I never told my partners. I once told a friend that I trusted because of having political identity but this person disclosed me to a lacho I am sleeping with. Sometimes I can be very angry, rebukeful. There is an activist in this country who told me, "You are not a woman, you wear a wig as a performance" and they still have a relation with that person. Or someone still keep contact with the person who disclosed me to my lacho. Such things make me alienated from the activism. It has never been like this with my family. I have never had a problem with my college friends, but I never came out to my colleagues. If I come out, I can face shade. I expect from the activists to be freed from these stereotypes. That is why I am open to my activist friends. Maybe my family and friends would also be discriminated, but they never shared this with others. Only that lacho asked about me to a friend, and that friend scored off him immediately, but my lacho never came and asked me."*

*"My parents told me, "we are sure that you got it abroad, right". They do not think that HIV is in Turkey. They have such a belief. They used to deport the drags they identified in Laleli. Cancan is the sexual health hospital in Cankurtaran district. They used to call it as "Genital Diseases Hospital". They would take prostitutes and transgender persons there and have them tested. The drags would ask me, "Have not you ever taken to Cancan?"... Because they were taking anyone they identified on the road. The newspapers were also writing the news about these deportations."*

Living with HIV can lead many difficult aspects for transgender persons. Like any HIV-positive person goes to the dentist, the dentist can avoid

treatment just because the patient is HIV-positive and may ask for exorbitant prices, the transgender persons may encounter the same discrimination at the medical stages of their gender reassignment processes. They may delay their processes simply because of the difficulties of the process, or their HIV status may be disclosed without their consent at various stages of the process. In addition, while the fear of disclosure of their HIV status pressured sex workers, sex workers' clients may create difficulties in another way. Clients can insist on having sex without a condom, and stigmatize sex workers who oppose them with HIV.

**IKH:** *"I do not remember clearly that much, but when persons who do not know about LGBTI+ issues and who do not know the field, when they talk about LGBTI+ persons, they always talk about HIV as well automatically, but I did not face anything directly against me. Doctors mostly have this attitude. When they see that you are a man, they codify you as a men-having sex with men. In the flow of the conversation, they sometimes use plural form of you and segregate you as a part of the community."*

*"I always kept myself in comfort zones. That is why I came out to persons who could accept it. I did not take any risks. I had partners having prejudices against HIV. When I met someone, for example, we had sex when we were dating. I come out only to persons that I sensed we will be together for a long time. I am not open to the sexual partners. Because I do not take them into my life. I do not want to carry the burden such relationships. As everything went well with that partner, I said it next day. "You had to tell me that" he said and "I do not have to share it with you" I replied. I drew the line very clearly. This time he said, "Of course you do not, but we are flirting and you lied to me". it made me feel bad. Then he stopped seeing me. This could have been worse. I was afraid to see anyone for a while to avoid to get into trouble. We never had anal sex after I told a partner I am positive. Several times, when my partner came beside me to the hospital, he was also considered as if he is HIV positive as well. They also label the persons around you. Some persons thought that I had too much sex. I tried to explain it is not like that. You face this if you are person who makes love to persons from lower socioeconomic levels, without limits by ignoring the hygiene. When I told a friend of mine "I never expected from you" my friend replied; by trying not to say anything bad, but it is considered as something not tailored for*

*my profile. They do not think you as if you cannot be with those types of persons. My friend told me "I am sad, it is not you. Why you?" They think, "this is an infection that does not match the middle-class status and you have so much sex."*

The reduction of HIV to the persons who are “from lower class”, “dirty”, “from ghetto”, “the “uneducated”, “having too much sex” is also phobic, and these views are produced to reinforce and reiterate the prejudices against these groups by the prejudices against HIV. HIV is a virus independent of classes, identities, and economic status and as its name says, it can only be attributed to the human self.

HIV should not be considered as a “punishment for crime” or “trouble”. Although HIV is a health condition, this punishment attributed to HIV is often described as the punishment for having sex, punishment for being LGBTI+. This is a phobic attitude.

**İÇB:** *“Usually my homophobic classmates were saying, “God has cursed persons like you, you are going to deal with this cursed disease”. When they found out that I am HIV-positive at work, they told me: “I think you should live in the Netherlands”. I was humiliated and insulted by my partners whom I said I am living with HIV. It triggers my depression. There is a gap between my previous sexual life and my current sexual life. I do not go out with persons because I want to comfortably tell persons that I am HIV-positive. But the persons I say this are ghosting me. I do not want to flirt anymore. It feels bad to go through the same process all the time. Only my sister in my family knows. Nobody has any idea about my life. I do not think that my circle experiences discrimination except me for this issue. Maybe it is a pressure on my family, but it did not reach me. But when my friends share my articles on Twitter or elsewhere, persons can send them direct messages by saying “Do not defend them, these are virus spreaders”. When I came out to one of my partners as HIV-positive he asked me “Are you sex worker?”. While I was in the military office, when I gave my exemption certificate to the officer, the officer looked at me and said “Did you go to Russia?”.*

Persons living with HIV may suffer from psychological disorders such as anxiety and depression as a result of discrimination and internalized pressure mechanisms. Unfortunately, there are no studies conducted in Turkey on effective psychological and physical health of HIV+ persons;

whereas the steps to be taken on behalf of the psychological wellbeing of persons living with HIV are ignored by public policies. Persons can even give up romantic and sexual relations in order not to face discrimination.

*"The first thing I encounter in a friend group is LGBTI+ phobia. Then I am throwing shade. This time, HIVphobia was the first thing that is faced in that crowd. When I do so, they asked me this time "Are you gay?" "No, I am bisexual." I replied. In the notification process, the doctor asked if I am gay. I have not encountered discrimination in the circle of friends. It is already a comfort zone. I am not going the places where I could possibly encounter it. I wanted to enroll for pool sometimes. I did not because they wanted a test. After a while, I stopped telling it to my partners. I do not want to tell it anymore. I have had problems with my partners twice. Then I stopped talking. After my diagnosis, all of my long-term relationships were with persons living with HIV, as a coincidence. It was not something I deliberately choose. Regarding whether my circle was discriminated for this reason, it is very likely that I cannot know. In my family, my father does not know about it."*

Those living with HIV can also discriminate against themselves. Persons may blame themselves, or they may refrain from using social facilities, such as going to the pool, in order not to experience further discrimination. As long as the persons living with HIV are not empowered, they may prefer such instead of enjoying their rights. In most of the interviews, it has been observed that persons are assumed to be LGBTI+ persons because they are living with HIV or they are considered as HIV positive on account of SOGIESC. In addition, persons' immediate surrounding and circle of friends may also be discriminated because they are knowledgeable doing advocacy about HIV, while discrimination against HIV can often manifest itself with hatred against sex work and prejudice against foreign nationals. In addition, exclusion and stigmatization can manifest itself everywhere, in every field, when it comes to LGBTI+ persons living with HIV.

## 8.7. Intersectionality of HIV with other fields

Human rights of LGBTI+ persons living with HIV are naturally affected by various situations such as disability, immigration, age, sex work, and

imprisonment. The process of persons living with HIV can lead them to face various different human rights problems in these situations. For example, within the scope of the regulations on nursing homes, those living with HIV are not admitted to nursing homes on account of "communicable diseases". Considering that LGBTI+ persons are also prevented from marrying and having children, this situation directly affects the rights to housing and health of the elderly and HIV-positive LGBTI+ persons. Another example can be given with regard to the persons with disabilities. In a system where family members are encouraged to take care of persons with disabilities, LGBTI+ persons with disabilities who have not good ties with their families cannot benefit from this support. Similarly, there are many cases where many HIV-positive LGBTI+ persons were isolated, disclosed because of their status or identity during imprisonment, so they could not enjoy their social rights in prison, or were unable to access the gender reassignment process if they are transgender. These two fundamental rights of HIV-positive LGBTI+ minors are violated as well as right to make decisions about themselves regarding their ages, their access to justice and education processes may be challenged. Such examples of multiple discrimination can be increased. Participants shared the following examples regarding such situations:

**KA**: “*We will experience another aging state and we have to fill this field. I am a political queer. If I am detained some day, the first thing I will think about is my medication. I do advocacy around me regarding this issue. I say “follow my right to health rather than my freedom in that case”. One of my mother’s biggest traumas is that I will die alone, and this has been engrained since my childhood. That is why I question the aging stage. I have no state and no society that can help me. That is why it is necessary to create this right. We have not conducted any study yet apart from 1 December. We also need to produce policies regarding the elder queers. We do not know anyway. I do not know, I do not know where they are. This does not mean that they are absent. We just pretend they do not exist.”*

**IAO**: “*Especially the LGBTI+ persons in aging faced a lot of certain taboos. I think we are considered by them as a bit brave in comparison. I think the regulations to be made should include them. For example, anonymous test centers should not be on a busy street, but rather on less busy streets to protect privacy.*

**AAA:** "Access to health is really trouble and very bad. I have a counselee right now; a foreign national moving towards an advanced stage with wounds over the body. This person cannot reach treatment, cannot go to own country due to both Covid and the lawsuits related to the family. This person cannot get treatment here. The medicine of the foreign nationals are cut. We are not referenced in any policy. These are not spoken anywhere. This is particularly hurtful and upsetting. Someone has to come out and raise the voice up. Due to inclusiveness, this situation cannot be ignored."

**IDI:** "it will be very classic but - I say social media. The reason why everything is so visible and powerful is social media. Government pressure also pushed persons to social media. Persons have their discussions there. (...) I can say that I am HIV positive in my comfort zones and I can say that you cannot have a phobia about me. I obtained this strength due to the associations, activists and my friends. There is something I have been thinking about recently. I am thinking of settling abroad at some point in my life. This can happen in any way. Via education or asylum seeking. Most of all, I am afraid of not being able to access my medicine where I go. I am older now. I do not know if I will suffer from other diseases or be bedridden. I do not know if I will be too afraid of getting the flu when I am 70 years old. On the other hand, we expect news about vaccinations. It scares me to be an old HIV-infected queer, especially aging alone."

**IKH:** "The process of first being acquainted with HIV, the support received, the service received, of course, changes. I think the main issue is person rather than generation. When they develop themselves from a human rights perspective, two HIV+ activists having different ages can have the same perspective. All HIV+ persons are going through a process. Every process is unique. I cannot tell the ones experienced the 90s era that why you could not think of the discourse: "I do not have to share my HIV status". But time passes and demands and claims change. It is necessary to keep up to date. Representatives of NGOs can say that we achieved many gains in this way. But looking at the past fifteen years, something else can be spoken. There are more persons, more literature, more claims."

**IDE:** "There is a generational conflict throughout the movements. There is a mistake caused by that the agenda has not changed. Persons living

*with HIV are aging for the first time all around the world. The young-old age cycle is completed for the first time. If subjects can talk a little more, current problems may become visible, such as being elder and the need for care, but the agenda does not change. It would be better if young persons living with HIV were to be treated as a situation, not as a health problem. Then, the agenda changes. The same thing has been spoken for 30 years and the same struggles are maintained"*

**I**EY: "Conflict ultimately serves something. It allows the parties to come closer or be far away. If there is no conflict, there is no communication. I observe that those diagnosed after 2010 are more aggressive. They want more action-based and faster results. It was slower for persons to do activism with open identities in the past. This aggression is an important thing to move forward fast. The perspective of our 40+ LGBTI+ persons does not coincide with the new generation. There is a movement is formed that demands a quick solution right now. The trauma of the new generation is also easier to solve because it is easier to find someone to ask questions. Communication tools also have an effect in this case"

"The world is now talking about HIV and aging. I am pushing myself to have plans as n HIV positive LGBTI+ person. I am trying to save money, because I will not marry or have children. I try to continue my life with persons I can consider as a family. There is an effort to create an alternative family for HIV-positive LGBTI+ persons over the age of 40. As a matter of fact, HIV-positive persons are not admitted to nursing homes according to the regulation. Currently, no lawsuit has been filed in this regard, but if it does, steps can be taken to renew the legislation. Because HIV+ persons will need more support as they get older. There should be a precedent for this. With regards to the prison, in one prison, there are six HIV-positive persons, they keep all of them in same ward. They intend to send the others to that ward as well. If the prison administration does not have the necessary information, it may be possible to take HIV-positive persons to single isolated spaces and to take them to have fresh air in an isolated way. Until these, the whole administration is already aware of the status of the person. There should be new regulations. In the case of foreign nationals, with a recent circular, it was decided that all foreign nationals except Syrians to benefit from health insurance for a year. But this is limited to one year. So are you going to cut insurance for a HIV-positive foreign national at the end of the year? Of course, there is no such problem for the registered ones.

In order for LGBTI+ persons and those living with HIV to age in a prosperous manner, the state should take steps in cooperation with the private sector and civil society, to abolish discriminatory legislation such as the regulations on nursing homes and remove the obstacles for the enjoyment of human rights by these communities via participatory and supportive public policies. However, starting from the fact that aging is a phase of every individual's life, the necessary anti-discrimination legislation, social security system and retirement policies should be developed in order for persons to be prepared for their senior years when they are younger and not to be traumatized due to their social backgrounds. Conversely, persons from these communities that are not covered by public policies may be forced into the cycle of poverty and deprivation in their senior years as in all stages of their lives.

## 8.8. The situation in the Covid-19 pandemic

The Covid-19 pandemic, which was included in our lives in 2020, also affected those living with HIV and LGBTI+ persons.<sup>5</sup> At first, they were accused of and were targeted by hate speeches of high-level public officials! In addition, conditions of confinement or returning to the family house increased the risk of domestic violence for many persons. Gender reassignment processes were interrupted due to the situation in hospitals. LGBTI+ labor, which is everywhere but especially in undocumented employment, which is already suffering from discrimination, has been dismissed. After the SSI announced that persons with chronic illnesses could purchase over-the-counter drugs from pharmacies if they have medical reports, some problems were encountered in accessing drugs. Likewise, during the period in which persons with chronic diseases were considered on leave, sometimes they could not get a medical report on chronic disease or faced the risk of disclosure to their workplace.

Participants' experiences in the Covid-19 pandemic are as follows:

**İEY:** "All hospitals became pandemic hospitals, and the Western Blot results of newly diagnosed ones delayed. Other PCR studies other than

<sup>5</sup> See. <https://www.kaosgl.org/haber/bm-devletler-covid-19-la-mucadelede-lgbtii-lerin-sesine-kulak-vermeli>

Covid were stopped. The devices became available with a doctor's notice. Those on routine treatment skipped their routine tests. The newly diagnosed friends also panicked, because they could not be sure about their resistance. Of course, it would be a more disastrous process if there were not the option of taking medicine before going to the doctor. On the other hand, there was a concern about what would happen if I got infected with Covid. Then there was a situation where those with chronic diseases were allowed to take leave, but some persons could not benefit because they could not say they are HIV-positive".

**İDİ:** "I was very scared in the pandemic that something will happen to us. I raised my perception immediately before coming to Turkey because I am Virgo. When I went abroad in January, I was taking my personal precautions at the airport. I was spraying disinfectant on my passport. I was nervous. I was saying that it will definitely come hither and yon until here. We have chronic disease; I thought it would be shady for us. Later, the associations explains that it have a neutral effect this gave me some relief."

## 9. Legal aspect of HIV

The legal and human rights aspect of HIV has become a more problematized area over time with the dimensions of the discrimination and stigma against HIV+ persons after the emergence of the virus. This chapter consists of the information on regulations aimed at preventing discrimination and facilitating access to services; as well as on a series of sub-clauses, including, but not limited to access to health services, and benefiting from public services by elder persons. In this sense, it contains a great similarity and intersectionality with the legal situation and claims regarding LGBTI+ rights.

Some of the legal aspect can be summarized as analyzing the awareness on the rights of HIV-positive and LGBTI+ persons, examining whether the information about the services provided is accessible and applicable publicly, and investigating how the awareness on the rights is implemented by individuals and institutions.

On the other hand, the other part of the legal aspect includes an analysis on whether the relevant legal protection exists; in particular on whether a legal hierarchy has been established between regulations and laws, between laws and the constitution, and between the constitution and international obligations.

This analysis was conducted by taking into account the Constitution which is at the top of the hierarchy of laws as well as the laws, statutes and regulations, which are at, lower level in that regard. The main axis of the analysis is for identifying whether there is a regulation in line with international standards and whether protection and policy are established by the laws.

In this context, the analysis has been conducted from the perspective of the International Covenant on Economic, Social and Cultural Rights and International Covenant on Civil and Political Rights which are known as twin binding covenants as well as European Convention on Human Rights which is the fundamental human rights convention of the Council of Europe system that Turkey is part of.

## 9.1. Awareness on the rights and accessing to justice

Given the discrimination and violations of rights faced by persons living with HIV, it should be said that access to justice is as important as access to health. Violations of the rights of persons living with HIV are frequently encountered in access to health, labour life and school life. We can see that there are intense violations regarding the right to education, non-discrimination, right to private life, right to work and access to treatment in the report covering February 2020 on the violations of rights by the Positive Living Association Ankara Support Center.<sup>6</sup>

In the article series "AIDS'li İğne (AIDS in Syringe)"<sup>7</sup> published on Kaos-GL.org; Attorney Hatice Demir, who provides legal advice on HIV, states on the violation of the right to privacy and the threats against those living with HIV as follows:

"Regarding the violation of the right to privacy, the legal tools we will use will vary depending on whom the violation comes from. For example, if the violation of privacy is caused by a doctor, applying to prosecutor's office and claiming for compensation may be possible as well as various administrative applications. If the violation is caused by a partner or friend, applying to the prosecutor's office and claiming for compensation may be possible. In addition to the violation of privacy, one of the most common issues faced is the threats. So there are threats and sometimes even blackmails on disclosing the information on HIV status. In case of these and of similar situations, we recommend persons to contact the associations working in the field and to get a legal support. I would like to say that getting counseling service from a lawyer before making legal applications helps a lot in preventing the violations of rights."

The majority of the participants of this study state that "I do not have the power to claim my rights, I do not want to be disclosed in the court in the process of claiming a remedy"; when they were asked, "if you face any discrimination, would you apply for a remedy?" It is one of the strik-

<sup>6</sup> For more information. See. [https://pozitifyasam.org/wp-content/uploads/Raporlar/Ankara%20Destek%20Merkezi\\_Hak%20%C4%B0hlalleri%20Rapor-1.pdf](https://pozitifyasam.org/wp-content/uploads/Raporlar/Ankara%20Destek%20Merkezi_Hak%20%C4%B0hlalleri%20Rapor-1.pdf)

<sup>7</sup> For more information. See. <https://www.kaosgl.org/haber/aids-li-igne-ihlale-karsi-adalet-ayrim-ciliga-karsi-dayanisma-hatice-demir>

ing findings of the study that the participants report their weakness or loneliness in case of facing discrimination. The participants' statements on the awareness of rights and access to justice are provided below:

**KAA:** “I know how to follow my legal process. I made research a lot on this issue. I know what to do if I am exposed to any situation. The thing I fear most is the exposure to violence. I know I have to do something if someone attacks me without giving me the opportunity to explain this. That is why I try to provide counseling for everyone around me in this sense. I tell the persons who consult me that they will get stronger after a while. I tried to live my process in a healthy manner. I did not know anything, and when I learned more, I got rid of my fears and became free. I have never resorted to judicial remedies myself, but I helped other friends in this regard. In one application, someone sent a message to an account I opened anonymously, saying, “You will die being racked with pain, you are danger to public health, you should not be among gays”. I learned who this person is, a medical student. I faced with this person and said “now we will go to court with you and you will prove that I will die being racked with pain”. This person got afraid of being disclosed and cried. This upsets me and I did not go to court.”

**IAO:** “I know my rights. Nothing like that happened to me either, but if it does, I do not have the courage to seek a remedy. I have not faced any major discrimination at the moment, but I am not sure what to do at that moment. I do not know if I can defend my rights while disclosing myself, or while trying to hide it more. It depends on the social situation I am in because I have to survive, I have to work. If it is learned, I may not find any job. In such a case, I would prefer to hide my identity until the end. Still, I inform my friends about this, even though I do not dare myself. I did not have any judicial process and I am not aware of the studies of other non-governmental organizations on this issue. I try to follow as best I can, though.”

One of the striking finding of the study is that the participants in the study inform and encourage other persons living with HIV on this issue, even if they can not go to court by themselves.

**KEK:** “I heard that I have rights. But I do not know if I can deal with it if something like this happens to me. I am afraid that when I apply to a legal process, I may be exposed to more phobias. I do not know if it makes

*sense to enjoy my rights. I am just learning these in the field of health. I was delighted when I learned about my right to change my medicine. I did not even know that I have a right to raise up my voice. I do not worry about the disclosure process, but if I am disclosed by someone, I can apply to the necessary authorities just to make them understand the consequences. I also shared a lot with my close friends on this subject and I think they changed something too. There is no association where I am. So here I can at least somehow support the persons I have around me. As if I heard it from someone else, I tell what I know and guide them. I have not had a process be submitted to the court".*

Unfortunately, those living with HIV are not sufficiently informed about their rights as well as about their health. Persons can learn about responsible authorities or NGOs either as a result of a recommendation or a research. In some cases, persons may not even be aware that they have the right to speak on issues that concern them.

**AAA:** *"I have not had a process be submitted to the court. I am thinking of suing if my medication is cut. Of course I am afraid of being deported. Immigrants and foreign nationals are constantly excluded in policies. This situation upsets me a lot. I know it legally, but this has a psychological aspect. There are things like claiming remedy when being subjected to discrimination, applying to court, but I still do not apply the legal process in the exclusions that I was exposed to. I think the disclosure situation will increase even more there. I have to come out to lawyer, judge and I will be discriminated again. So I am afraid. That is why I am trying to fix those persons, but I did not apply to any authority. I mostly tried to solve it directly or I paper over it. Still, aside from myself, I keep persons informed. For example, when our last counselee told about someone else's HIV status, I warned him. I am also trying to provide the necessary guidance."*

Despite almost all of the participants have somehow contact with LGBTI+ and HIV organizations, are responsive to human rights issues and provide support for raising awareness, they feel powerless when they face an incident can be submitted to court. This has revealed that how deep and institutionalized the discrimination against LGBTI+ and HIV+ persons. The obligation of the state here is to build trust and to increase the access to justice among persons from this community, to carry out campaigns for this purpose, to facilitate judicial processes, to

take measures to protect personal data in these processes and to intervene in litigation processes in appropriate cases.

**İEY:** “*I am aware of my rights but it does not happen because I am not giving it chance. Now when I go to the dentist, if dentist is a hard case, I come out for example and they say no problem or something. I have never faced anything. There were only small rumors. Of course, I did not apply to an authority. I think it is because I am on the other side of the table. I am mostly providing information. I have been providing information to thousands of persons for years. At first I really think finding the right resources are really good for coping with it. The support of close friends, associations and consultants are very important. I did not face personally. Something like this happened: in the past, we used to get on the shuttle around Turkish Airlines to go to the Anti-Homophobia Meeting. When I was trying to catch it, the police asked for my ID card, wanted to search my bag and saw my drugs and asked, “What are these?” “For my treatment” I replied. “Are you sure that those are not narcotics?” The police asked. I said, “You have to be sure. What are narcotics and how can you find them?” The police said “we have to take it to the lab.” I said, “you are talking nonsense, look, the bus is there. I have to catch it up”. Then I showed the photo of the drug from Google, tried to find something from the e-devlet. The police said, “You are right, but we do not know, it could be narcotics”. I called the association’s lawyer at night. I tried to explain. The lawyer wanted to talk to police on phone and said, “You have to have a list. It has to match it. So my friend has a bus to catch, I ask for a release”. Then they released me and I went.”*

While peer counseling is useful in the diagnosis processes of persons living with HIV, it is also beneficial for them to get legal counseling regarding legal problems. HIV organizations and LGBTI+ associations working on HIV can be recommended for legal counseling and peer counseling.

**İDİ:** “*I have never had a process submitted to the court. We also have our own rules. For example, if I am exposed to someone's phobia, I will report them to their organization. I do not trust the justice of the state. I trust our judgment. If something happens to me, I may not want to deal with that process. I do not think I know my rights very well. If I come across something like that, I call associations. Despite this, I try to provide minor guidance. I am afraid to mislead them because I am not competent. I find it more correct to guide them to institutions and activists.”*

**İKH:** "I have never had a process submitted to the court. I do not think I know my rights fully. I personally can throw something I come across shade; from any human rights perspective. After all, law is not always based on human rights. What is the legal equivalent of my own defense? I do not know this. I tried to explain myself with my own knowledge. It is not legal, but I do it regarding the human rights. I have converted my lawyer friends like that. I am trying to make them to interpret in line with human rights."

The HIV issue is not only a health condition but also a human rights issue. For this reason, it is necessary to interpret HIV from a human rights perspective. As a matter of fact, the violations that persons living with HIV are exposed to should be studied by national human rights institutions and these institutions should shed light on the public administration and society in the fight against HIVphobia and LG-BTI+ phobia.

**İAE:** "I thought of suing those who spread my private information. Then I said it is not worth to do it. It would be tiring. Actually, I want to deal with precedent cases, but I avoided it in general. I know my rights superficially. I am aware of my right to privacy, but I do not know in detail. If necessary, I think I can reach the association when necessary. Since I am open, those who are diagnosed can write to me about my status. I provide solidarity as much as I can. I am in a position to provide support"

**İÇB:** "I know my rights now. They taught me by beating it into my head. I did not apply to an authority because I did not have a lawyer behind me guiding me and I am not in a position to endure another process. I talked with a lawyer of a LGBTI+ association I intended to make a report by a symbolic case, but I was informed, "Nothing comes out of this". It is not possible for me to stand alone. I am an open HIV positive. I am open to the persons around me. I am trying to provide information to others. I want to express this myself."

**İDE:** "I had a judicial process with my ex-partner. At that time, information on HIV was also mentioned in some texts. I think I know my rights. I went to the chief physician when I faced discrimination but it remained unsolved. They did not contact me. I try to provide information as much as I can"

Policies in the field of law need to be developed in order to protect the privacy of persons living with HIV in judicial matters on account of HIV. These policies should protect the privacy of those living with HIV and minimize the difficulties of disclosure required during the trials. In addition, lawyers, judges and prosecutors should be informed about HIV in a human rights oriented manner.

## 9.2. Legislation

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With the emergence of information on HIV in the world, stigma and discrimination against HIV-positive persons have taken their place next to other forms of discrimination. This situation has pushed persons living with HIV to a more vulnerable area in accessing rights, and the human rights of persons living with HIV have emerged as a separate topic in the general human rights struggle in order to prevent violations caused by the lack of policy or by public officials.

In the most general sense, the two main pillars of the problem for HIV-positive persons are stigmatization and discrimination. Stigmatization in its broad sense is making negative accusations against persons for a characteristic that they have unwillingly, characterizing these as an embarrassing characteristics, associating it with the reputation of the persons and the loss of status these cause. Discrimination against those living with HIV is also one of the consequences of this stigma, and is often shaped by the systematic or singular emergence of status that does not have the rights of everyone.

One of the important means of combating stigmatization and discrimination is that states' interventions to prevent or impose sanctions on discriminatory treatment against individuals. In this case, the perpetrator of the violation is not a government official, but any third person who exposed the person to discrimination. However, the state tries to prevent discrimination before it begins, by using its authority to punish the act of this third person or by imposing sanctions through another tools, by showing the results of the discriminatory treatment to this person and provide messages to general society how to act in case of discriminatory treatment.

Undoubtedly, discrimination carried out directly by state officials is another dimension, and the state should both develop policies to prevent this and impose effective sanctions if it occurs.

Here, in this study, a series of regulatory documents, starting from the Constitution, which is at the top of the hierarchy of norms to regulations, which are elements of subsidiary legislation, will be analyzed from the perspective of whether it includes policies regarding HIV status. Within the scope of this review, both the state's stance against its negative obligations and whether it has taken the necessary action will be discussed. The review will be carried out by accepting the standards set out in international human rights documents as the criterion.

There are persons everywhere where there is life, so of course the absolute inclusive review must cover analysis of all laws and regulations in Turkey. But that means millions of pages of written documents, and it is not functional either. Instead, using existing reports, the problem areas were focused on, the legislation that could have an impact on those problem areas was listed, and the review was conducted through this listed legislation.

## **A. THE CONSTITUTION (Published in Reiterated Official Gazette No. 17863, on 09.11.1982)**

It is possible to consider the situation of benefiting from the rights for persons living with HIV in terms of protective provisions under the title of each article, and it is also possible to analyze these articles limited to those regarding fundamental rights and freedoms. While observing the published reports, it is seen that violations of rights are concentrated on certain issues regarding HIV-positive persons. Under this headline, the review will analyze the Constitution and the articles of the European Convention on Human Rights, which are part of it pursuant to Article 90 and Article 148 of the Constitution, which can provide a protective umbrella for violations revealed in the mentioned reports.

While observing the Constitution in terms of provisions related to our field of work; the below mentioned provisions: equality before the law (10), personal inviolability, material and spiritual entity of the individual (17), privacy and protection of private life (20), protection of the family

and rights of the children (41), right and duty of training and education (42), freedom to work (48), the right to benefit from healthcare services (56), the right to housing (57), the right to social security (60) are of particular importance.

It should be noted that there is no provision in the Constitution that clearly prohibits discrimination. However, Article 10, which guarantees equality before the law, reveals the constitutional status of equality as a means of preventing discrimination. However, as can be seen in the regulations that provide limited equality in other laws, the Constitution also lists certain forms of discrimination without covering all and it provides an omnibus provision includes all residuary not specifically mentioned in a limited way: "***All individuals are equal without any discrimination before the law, irrespective of language, race, color, sex, political opinion, philosophical belief, religion and sect, or any such considerations***". Although this limitation can be associated with the limited consideration of human rights awareness and international law principles in the country and around the world in 1982, when the Turkish Constitution was adopted, the fact that this article was not comprehensively addressed later in more than ten amendments following its first announcement shows that the point of view in that regard has still maintained.

Prohibition of discrimination is also addressed in the Article 14 of the European Convention on Human Rights (ECHR). However, the mentioned article prohibits discrimination specific to a right recognized in the convention. However, when there is a right not recognized by the ECHR (for example, the right to utilization of the coasts), article 14 of the convention cannot be applied. However, Protocol No. 12 to the Convention has brought general prohibition of discrimination. While the Republic of Turkey have signed this protocol, since it has not duly performed the ratification process of the protocol, this provision is not yet binding.

However, Article 10 of the Constitution, which prohibits discrimination, provides a wider protection than Article 14 of the ECHR, since all laws passed by the parliament should not remove the right of persons to be equal before the law. The problem here appears briefly in terms of positive and negative obligations.

As it is known, the violation of the negative obligations of the state in terms of rights is the violation of the rights of individuals by an active action of the state. For example, refusing to allow an association to be founded by persons living with HIV to operate for any reason would be a violation of the right to organize. A positive obligation gives the state an obligation to take action in order to ensure the enjoyment of a recognized right. This obligation can be observed more easily during the exercise of the powers delegated to the state through constitutions called social contracts. For example, individuals have the right to claim that their privacy to be respected. Securing this right may sometimes require an action by the state. If the state does not use its sanction power against the person disclosing without consent, as in the example of the public announcement of a persons' status by third parties against their own will, it will be a violation of positive obligation.

Another problem in terms of the Constitution is how the ways will be formed to solve the problems that arise in the case of implementation of non-fully inclusive legal documents or subsidiary legislation in view of the non-practical generality of these documents. The Constitutional Court, which started accepting individual applications since September 2012, has had a function that solved this issue to some extent, but the fact that individual applications cannot be made to the Constitutional Court in terms of rights that are not in the common protection area of the Constitution and the ECHR is an important gap in that regard.

Article 17 of the Constitution on personal inviolability by stating "***Everyone has the right to life and the right to protect and develop his material and spiritual entity***"; explains that everyone has right to life and the right to develop their material and spiritual entity without exception. This is a protective norm for HIV-positive persons in terms of the obligation to respect their private life, since the Constitutional Court addresses the individual applications made to it in terms of respect for private life, in the context of Article 17. This article not only guarantees persons in terms of violations of the right to life, but also provides a guarantee in cases where the state does not take positive action to ensure the development of material and spiritual entity.

Article 20 of the Constitution also guarantees private life by mentioning it as a concept this time. According to this "***Everyone has the right to***

**claim respect for his private and family life. Privacy of individual and family life may not be violated.**" This regulation is in line with Article 8 of the ECHR. Of course, this necessitates the positive obligation of the state, because the violation of the right to respect for private life can be violated not only by an action of state but also by an action of individuals. On the other hand, in the continuation of the article, it is stipulated, "**Everyone has the right to request the protection of their personal data.**" This is particularly important as it shows how the status is restricted after it becomes known to state authorities. The exception to the rule is specified in the article. According to this, "**Personal data can be processed only in cases envisaged by law or by the person's explicit consent.**" Therefore, the Constitution has stated that the protection area provided to persons living with HIV can be limited by a law that can be enacted by the parliament with the exception it creates, and as it will be seen in the later stages of the study, the Law on the Protection of Personal Data did not seek the consent of the person in the recording of health data, which it considers as private, and implemented this exception. Therefore, the nature of this constitutional protection for HIV-positive persons has been seriously eroded.

Although Article 41 of the Constitution is not sufficient for children, it provides a limited area of protection. According to this "**The State shall take the necessary measures and establish the necessary organization to protect peace and welfare of the family, especially mother and children, and to ensure the instruction of family planning and its practice.**" The consideration of the rights of the children only in the context of the family is a problem in itself. In addition, the creation of the upper umbrella for the protection of children creates a mechanism for children living with HIV. In this respect, it is a positive regulation.

The freedom to work is regulated in Article 48 of the Constitution. According to this, "**Everyone has the freedom to work and conclude contracts in the field of their choice**" In the second paragraph of Article 49, which defines working as a right and duty, the obligations of the state regarding the employment of individuals are emphasized. According to this, "**The State shall take the necessary measures to raise the standard of living of workers, and to protect workers and the unemployed in order to improve the general conditions of labour, to promote labour, to create suitable economic conditions for prevention of unemployment and to secure labour peace.**"

The Constitution does not make a principle-level determination regarding discrimination in working life, and with the second paragraph of its Article 48 that approaches work as a duty assigned to the citizens as well as being a right, it does not impose a positive obligation on prohibition of discrimination.

Discrimination related to working life shall be addressed inevitably at the principle level within the scope of the Article 10 of the Constitution. However, while this article enumerates the forms of discrimination in detail, as stated above, it does not include many forms of discrimination, including sexual orientation, gender identity, gender expression, and health status in detail. However, against those living with HIV, discrimination occurs at many stages of employment, from the employment processes to the conditions of work; from violation of the right to privacy regarding HIV status in the workplace to the processes of cease of employment.

Although in the introduction of Article 56 of the Constitution, such a statement: "***Everyone has the right to live in a healthy and balanced environment***" describes a policy by taking into account only the environment while not including the human being; in the third sentence, the provision: "***The State shall regulate central planning and functioning of the health services to ensure that everyone leads a healthy life physically and mentally, and provide cooperation by saving and increasing productivity in human and material resources.***" imposes general responsibilities on the state in order to create a policy on health, whereas the following sentences impose responsibilities on the state to implement the policies regarding the standardization of healthcare institutions.

In Article 57 on right to housing, it states, "***The State shall take measures to meet the need for housing within the framework of a plan that takes into account the characteristics of cities and environmental conditions, and also support community housing projects.***" However, it leaves the way of addressing the question of what to do if persons are prevented from realizing their right to housing by discriminatory treatment again to the Article 10.

Article 60 of the Constitution by its first sentence "***Everyone has the right to social security***" clearly expresses the policy regarding the right to social security.

Constitutions are the documents of fundamental rights. While the most important functions of it to limit the area of the state against its citizens, it also shows the responsibilities of the state for the acquisition of the rights in the constitution. Considering the current version of it, it is possible to say that the constitution does not contain a clear and decisive policy in terms of discrimination, and the statements about how exceptions on rights will take place in the articles are much longer than the explanations made to explain the essence of the right.

The result of constitutions being fundamental documents is that their content is general. They are expected to set forth general principles and policies, not detailed regulations. They are more effective in meeting the needs of the changing eras to the extent that they reveal general principles and policies. Apart from this, a determination of rights in the constitution does not make a change in the lives of individuals and does not guarantee their human rights unless a legal regulation is made in line with the policy in the constitution. Therefore, legal regulations that reveal the general principles of implementation and of their details to some extent are of great importance.

As an example, the equality article of the Constitution emphasizes the equality of everyone before the law. However, as it will be analyzed below, if the discrimination is on account of gender identity is not listed among the forms of discrimination prohibited in the founding law of the Equality Institution, the result of this will be that although not accepting a cis-person to a hotel is subject to sanctions by the Institution, not accepting a trans woman to the hotel will be excluded from those sanctions imposed. This reveals that the fact that the general principles of the constitution are not reflected in the law, even if it is incomplete, makes the provisions in the constitution dysfunctional.

## B. HEALTHCARE

**1. The Basic Law on Health Care (Published in Official Gazette No. 19461 on 15.05.1987):** The Law aims to regulate the basic principles of healthcare services by Article 1 of this law. Consisting of 12 articles, 17 additional articles and 12 provisional articles, this law entered into force in 1987 and 32 amendments to this law were made. The law can be described as a document that should be implemented in case of conflict

with the basic law on health and the other laws due to their special natures. While the law contains provisions related to healthcare services provided by the public, it also contains provisions related to healthcare services provided by the private sector. In addition to these, the fact that it includes provisions regarding the standards that the healthcare service should have makes the law more significant. Again, the fact that it contains provisions on informing citizens in the field of health provides a legal basis especially for raising awareness studies.

Especially Article 4 on “General Principles” is quite comprehensive and contains detailed provisions regarding all parties of the field of healthcare service. The provisions contained in this article can be listed as: planning, coordinating and supporting healthcare institutions and organizations throughout the country; organization of preventive healthcare services and the principles to be followed during the provision of this service; mainstreaming healthcare institutions and determining the prices; **to follow healthcare processes and to do this via using electronic tools**; the general employment planning of healthcare staff and the role of the academy in this regard; the coordination of the healthcare institutions under the jurisdiction of different ministries or public institutions; collaboration between public institutions, professional organizations and non-governmental organizations, especially regarding **training of the citizens on the prevention from diseases, healthy environment, nutrition, mother and children health and family planning, etc.**; production of the materials used in healthcare; the studies on the prevention of the disabilities that children are born with; the studies on the reduction of risks related to metabolic disorders that can affect a newborn baby and carrying out processes related to the production of equipment used in rehabilitation services.

Other articles other than that regulate more specific issues such as employment of the staff, assignments, and specialty in medicine and do not consist provisions related to general principles.

In line with the purpose of the law, it would be a legitimate expectation that the general principles to cover ethical obligations and human rights standards that must be followed during the provision of healthcare services. However, the law does not include any reference to ethical or individual rights, except for the additional article 10, which covers standards on equipment or drugs to be used on humans. In general principles,

healthcare services are considered as a product purchased and sold in the market and does not provide any regulation on issues such as patient records, general human rights standards to be followed, privacy of patients.

With its current version, it does not contain standards other than equipment and drugs to be used on humans, not only for HIV-positive persons, but also for all recipients of healthcare.

## **2. Law on the Promotion of Social Assistance and Solidarity (Published in Official Gazette No. 19134 on 14.06.1986)**

The purpose of this law is provided in the Article 1 as: "assisting the impoverished and needy citizens and the people who were forced to come or accepted to Turkey; insuring precautions to consolidate social justice and to obtain a linear income distribution, promoting social assistance and solidarity". It is also stated that general health insurance holders under the 60/1-c provision of the Law No. 5510 on Social Insurance and Universal Health Insurance Law are within the scope in terms of premium obligation. From this, this law is relevant to those living with HIV in that regard.

Since the law mainly consists regulations regarding the needy persons, the evaluation in terms of HIV status will be provided within the scope of the analyze made on the Law No. 5510.

## **3. Law on issuance of Green Cards for the citizens who are incapable to pay for Health Care Services**

Since this law was abrogated on 01.01.2012 pursuant to the last/article 106 of Social Insurance and Universal Health Insurance Law No. 5510 and was taken under the control of Social Security Institution in accordance with the decision to unify all the systems under one roof, the previous review of the green card will be made within the scope of the Law no. 5510.

## **4. Law no. 5258 on Family Medicine Pilot Implementation (Published in Official Gazette No. 25665 on 09.12.2004)**

Besides the purpose of regulating the personnel affairs of the staff, the law also aims to "improve primary healthcare services, focusing on pre-

ventive healthcare services in line with the needs of persons, and keeping personal medical records". This makes the law especially important for those living with HIV, in terms of access to the right to health, respect for the right to privacy.

Family physicians are the doctors providing primary healthcare services, whether they are specialists or not. Therefore, the first symptoms considered to be caused by any disease, regardless of the HIV status, cause individuals to go to their family physician. This increases the importance of the family physicians in the whole health system.

According to the Article 2 of the law on definitions, the family physician is the doctor who is obliged to provide personal protective health services and primary care diagnosis, treatment and rehabilitative healthcare services to every person, in a comprehensive and continuous manner in a certain place regardless of the age, gender and disease of the patients. However, drawing the boundaries of this equal treatment obligation, which is in line with the prohibition of discrimination in the conventions and the Constitution, appears as a deficiency. In addition, the fact that the legislation on health qualifies positive HIV status as a disease by itself and according to this article, the fact that the disease cannot be the type of motivation in discriminatory treatment appears to be a positive aspect for those living with HIV.

Within the scope of this research, the gaps identified in the Patient Rights Regulation are also contained in the Law on Family Medicine. Although within the purpose of the law; the provision on "keeping personal health records" has been provided, the principles and rules to be followed while keeping these records are not provided. Therefore this constitutes a deficiency.

## **5. Law on Blood and Blood Products (Published in Official Gazette No. 30616 on 05.02.2018)**

Considering the fact that the Turkish Red Crescent Society is exclusively authorized institution for procedures such as blood donation and preservation and that the Law on Blood and Blood Products will be implemented during these, the importance of this law is understood in that regard. As a matter of fact, the purpose of the law is stated in the first ar-

ticle as “regulating the procedures and principles regarding blood, blood components and products”. In addition, the provision within the general principles stating that “It is obligatory to register and store the data on the collection, record, analysis, processing, storage, making available, distribution and use of blood, blood components and products and all the other data related to blood donation, blood donor, authorized institution, place of use and recipient for thirty years in written format and electronically” requires various safeguards to be introduced by law in terms of the right to privacy.

However, there is no legal guarantee regarding who will be able to access this information, which is stated to be transferred to electronic media, for what purpose the information will be stored, and whether special measures are taken regarding the access to the information on HIV-positive persons. Similarly, in Article 6 regarding criminal provisions, there are no sanctions imposed against the institutions or the staff of the institutions who share such information without consent, eliminating the information security.

## C. SOCIAL SECURITY

### 1. Social Insurance and Universal Health Insurance Law No. 5510 (Published in Official Gazette No. 26200 on 31.05.2006)

This highly comprehensive law consisting of 109 articles, 19 additional articles, 81 provisional articles; which constitute the basis for 426 subsidiary legislation such as bylaws, regulations, declarations, circulars, decisions and which has been amended 71 times by either amendments or the decisions of Constitutional Court after its entry into force, aims: *“to insure the individuals in terms of social insurance and universal health insurance; to lay down individuals who will benefit from such insurances and the rights to be granted, conditions for benefiting from such rights, and the methods of financing and covering; and to regulate the procedures and principles regarding the execution of social insurance and universal health insurance.”*

Considering its scope and purpose, and considering that it is a source for other practices, the systematics of this law and the principles and values it carries/does not carry are very important.

First of all, it should be noted that the scope of this law just covers the insurance holder and their dependents the spouse, children under 18, the mother or father within the context of the Turkish Civil Law, whereas it does not cover civil partnerships. In this sense, it would not be wrong to say that the way the law is formed in the light of systematic heteronormativity. Considering that the law shapes not only access to the right to health indirectly but also it shapes the social security system in general by considering all kinds of insurance regarding old age, maternity, unemployment, death, etc.; it is possible to say that legal heterosexual couples are the only targeted holders in terms of partnerships. This situation inherently creates an attitude difference between straight HIV-positive persons and non-straight HIV-positive persons. Although it is claimed that there is an accessible health regulation in Turkey in terms of the treatment for HIV+ persons in general; the discriminatory nature of the social security system as a whole indicates the inequality in the other components of healthcare or the other areas of human life affecting health.

The medical premiums regarding HIV-positive persons covered by the law are already covered in the context of their general insurance. The income status of HIV-positive individuals who are working unregistered without the insurance is determined by an income test, which will be carried out considering the income of everyone living in the household where the person lives. If the income test is below the minimum limit, they can benefit from the healthcare services within the scope of this law, without being charged with premiums from them.

As a result of Article 14 of the law, AIDS caused by HIV is classified as an occupational disease. However, in the study of "Occupational Diseases"<sup>8</sup> published by the Ministry of Labor and Social Security, Labor and Social Security Training and Research Center, AIDS is defined as a common occupational disease in terms of "healthcare staff working in healthcare institutions and laboratories". In this case, the unregistered sex workers are not being able to benefit from the rights provided in the Article 16 of the law, since they are not considered from those whose biological sex assigned at birth is female, who are allowed to work in

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<sup>8</sup> See. <https://ailevecalisma.gov.tr/media/1340/meslek hastaliklari.pdf> p. 29

brothels according to the General Public Health Law or who have undergone the gender reassignment process in the context of legal recognition of their gender identity according to Article 40 of the Turkish Civil Code. On the other hand, considering the above limitation, it cannot be said that these rights can be enjoyed in absolute quality by "brothel women", which is the wording used in the law. These rights include receiving temporary or permanent incapacity payment in line with the inability of the positive persons in the AIDS stage to participate in labour force, in obtaining income to be given the right holders in case of death, in obtaining the marriage allowance to be given to the girls provided income, and in obtaining the funeral allowance to be given to the deceased. The same problem exists for invalidity allowance in case of disability.

As stated above, all of the insurance holders are general health insurance holders. In terms of those who are not holder, i.e. those who do not work in a registered work, an income test will be made. On the other hand, the fact that "international protection applicants or status holders in Turkey and stateless persons" are considered as general health insurance holders without being subject to an income test provides HIV-positive refugees with limited access to healthcare. On the other hand, Article 67 on "Conditions for benefiting from healthcare services" accepts the treatment expenses for the category of "contagious diseases with notification obligation" as an exception, in line with other legislation analyzed within the scope of this study. Therefore, it is not compulsory for HIV-positive persons to meet the conditions stated in this article.

## **2. Law No 2828 on Social Services and Child Protection Agency (Published in Official Gazette No. 18059 on 27.05.1983)**

The purpose of this law is stated in Article 1 as "to regulate the principles and procedures of the social services provided to families, children, persons with disabilities, elder persons and other persons in need of protection, care or assistance, and the establishment, duties, authorities and responsibilities, activities and revenues of the organization established to provide these services". The law also covers the beneficiaries. Although it lists the categories in the section on purpose, it is possible to say that everyone can be included under the umbrella of service pro-

vided to other persons. On the other hand, the elder persons in need are determined as the direct beneficiary. In terms of institutional scope, orphanages, nursing homes, women's or men's guesthouses, community or family counseling centers, active living centers, and home-type social service units are considered as social service centers. The common name of the institution affiliated with the law is the "Social Security and Child Protection Agency".

The article on general principles "*prohibits in the provision of social services discrimination based on class, race, language, religion, sect and regional differences*". In legal documents where the content is limited, it is common to exclude the other forms of discrimination outside the scope of protection. For example, in the Law No. 5258, "disease" is listed under protected categories and it is stated that no discrimination is allowed based on this. In Law on Human Rights and Equality Institution of Turkey analyzed within the scope of this study, the fact that there is no statement regarding gender identity and sexual orientation causes the institution to refrain from identifying the violations of human rights of LGBTI+ persons. As such, like sexual orientation, gender identity and sex characteristics are not specified, the fact that HIV status or diseases and medical conditions are not specified among the sub-paragraphs of Social Services Law that prohibits discriminatory treatment appears as a deficiency of policy in terms of protecting human rights.

## D. FUNDAMENTAL LAWS

### 1. Turkish Civil Code (Published in Official Gazette No. 24607 on 08.12.2001)

All relations between individuals, i.e. everything related to civil life, are regulated by the Civil Code having fundamental characteristics. As a matter of fact, in the Article 5 of the law, it is stated, "The general provisions of this Code and the Code of Obligations apply to all civil law matters as deemed appropriate". Therefore, this law, which can be called as the constitution of any communication that is not related to the functioning of the state, has a special place compared to other laws. In other words, if there are provisions that are not regulated in hundreds of laws such as the Code of Obligations, Labor Law, Commercial Code, Law on Associations, it will be necessary to look at the provisions of the Civil

Code. What makes this law, which consists of 1030 articles, important is that other laws are seen as complementary to this law.

On the other hand, the highly important provisions on the profession of judges, which will resolve any dispute before the judicial bodies are; Article 1: Application and sources of the law and Article 4: Judicial discretion. According to this, "where the law confers discretion on the court or makes reference to an assessment of the circumstances or to good cause, the judge must reach its decision in accordance with the principles of justice and equity". Whereas in Article 1, it is stated that "In the absence of a provision, the judge shall decide in accordance with customary law and, in the absence of customary law, in accordance with the rule that it would make as legislator". Undoubtedly regarding the general principles in this code enacted in 2001, there can be additional articles provided from the resources such as Constitution, universal principles of law, international treaties Turkey is a party to; the scope of protection in terms of the rights of individuals can be expanded. Unfortunately, this scope, in which the general principles are provided in a limited format, underlines a very wide discretionary power while referring to the customary law and the way the judge chooses to act.

The fact that the basic regulations preventing discrimination are included in this law since it is one of the most fundamental laws it can be a guide for how other laws should be interpreted. The preliminary provisions do not contain any recommendations to avoid discrimination between individuals.

On the other hand, with its content stating that "all human beings are equal in enjoying rights and fulfilling obligations within the boundaries of the rule of law" under Article 8 on competence in enjoying the rights is positive in terms of providing a general framework.

The emphasis on equality is also in Article 68, which expresses the principle of equality in the context of the Rights of Members of An Association, as: "Association members have equal rights. The association cannot discriminate between its members in terms of language, race, color, gender, religion and sect, family, group or class; nor adopt any practices deteriorate the sense of equality or give privileges to some members for these reasons".

Considering that other special laws are complementary to this law, it can be argued that the protective provisions in those laws or the provisions prohibiting discrimination *per se* can also be applied in interpersonal relations. However, not including a protective and non-discrimination content in the civil code in terms of LGBTI+ persons and HIV-positive persons is entirely due to the political preferences of the lawmakers. In this sense, it would not be wrong to say that the civil code, which is regarded as the basis of laws regulating private law relations, does not contain a policy.

## **2. Turkish Penal Code (Published in Official Gazette No. 25611 on 12.10.2004)**

Considering the theoretical acceptance that individuals delegate their powers to states in imposing punishments and enforcing sanctions, it is a universal fact that penal codes are of key importance in terms of indicating for which personal actions the state uses its power to impose punishments. Although it is a method that violations that may be directed from individuals to individuals can be subject to sanctions through compensation lawsuits to be filed to general courts, it is stated in the Council of Europe system and the decisions of the European Court, which is the supervisory body of the European Convention on Human Rights, that the legal remedy may not be sufficient in combating discrimination and that criminal sanctions may be required. This highlights the significance of the sanctions for ensuring non-discrimination in terms of sexual orientation, gender identity/expression, sex characteristics/intersex status (SOGIESC) and HIV status, claiming respect for private life, guaranteeing the obligation of service and goods providers to behave equally in accessing goods and services, preventing the sharing of personal information with third parties without consent.

In terms of criminal theories, the use of criminal power has a mixed effect. The punished persons will directly associate the refusal to do the action defined as a crime that led to their punishment with the sanction imposed on them. In terms of third parties other than the victim/survivor and perpetrator of the crime, punishing the perpetrator is important in terms of revealing the consequences of this action for the person.

Therefore, the way in which the criminal power is used is very important in terms of showing what kind of actions the state has taken in terms of preventing the victimization on account of SOGIESC and HIV status.

With the period of TPC No. 5237, actions defined as misdemeanor were regulated in a separate law, and TPC only covered actions that were defined as crimes and offences. The law, which includes its objectives in its Article 1 such as to protect individual rights and freedoms, peace in the community and to prevent the commission of offences, also includes detailed regulations regarding which penalty or security measures will be imposed for criminal offences.

Article 29 on “unjust provocation” is a provision on reducing the sentence that is generally criticized by NGOs. Accordingly, the penalty to be imposed shall be reduced by one-quarter to three-quarters depending on the severity of the provocation. There are judicial decisions in which the non-sharing of the information on sexual orientation, gender identity or HIV status with the sexual partner is accepted as an act of provocation.

One of the most frequently reported violations in terms of LGBTI+ and HIV-positive persons is the threat to disclose identity or status. In ordinary offences of threat, the realization of the action only produces one time victimization. However, it can be easily argued that the overall effect is quite high when considering the effect on the victim of the threat action towards the disclosure of identity or status without consent and the discriminatory culture in the society even if the act is not realized.

On the other hand, it is known that disclosure of a person's HIV status through involuntary or voluntary means may lead to prevent them from accessing to certain rights. HIV-positive persons can be excluded from educational institutions and their right to education can be violated. Their labour life can be interrupted just like LGBTI+ persons. In some cases, especially in the field of health, they are prevented from using public services on account of their HIV status. It is not possible to think that there is an equal treatment in the exercise of political rights, even if there is no such case. In addition to these, it can be thought that, similar to LGBTI+ persons, inviolability of domicile of those living with HIV can be violated more frequently in some cases.

One of the areas where violations are most intense for HIV-positive and LGBTI+ persons is the discrimination faced in both the recruitment and dismissal stages of employment and the treatment contrary to the equality obligation in the workplace.

For this reason, in case of the above-mentioned criminal acts, which are regulated in the “Offences Against Liberty” section of the law, occur on account of identity or HIV status, it is clear that more effective legal policies shall be in force. Unfortunately the law does not regulate the HIV status as an “aggravating motive” nor SOGIESC and it vitiates the value of its deterrence by not pursuing a legal policy equivalent to these factors that aggravate the effect of discrimination.

In the reports or narratives of non-governmental organizations working on LGBTI+ and HIV issues in that regard, it is stated that they are clearly exposed to discrimination in access to goods and services, especially in cases such as rental of a house, the landlord and the residents of the apartment or site where the house is located do not let them to rent a house by oppressing them. Therefore, in that regard, Article 122 of the law on Hatred and Discrimination has a special place.

The article is as follows: “Any person who (a) Prevents the sale, transfer or rental of a movable or immovable property offered to the public, (b) Prevents a person from enjoying services offered to the public, (c) Prevents a person from being recruited for a job, (d) Prevents a person from undertaking an ordinary economic activity on the ground of hatred based on differences of language, race, nationality, color, gender, disability, political view, philosophical belief, religion or sect shall be sentenced to a penalty of imprisonment for a term of one year to three years.”

Although the fact that this act, which is not regulated as a crime in the Turkish Penal Code No. 756, was regulated in the new law period may seem like a progress, the norms prohibiting discrimination should not make a choice between discrimination motives due to their nature; otherwise, the norm itself will turn into the source of discrimination.

The article has been amended three times and its title “Discrimination” has been changed to “Hatred and Discrimination”. As it can be seen,

the realization of the action in the law article, which finds an application area according to the motivation of discrimination, is limited to language, race, nationality, color, gender, disability, political opinion, philosophical belief, religion or sect. "Health status" and "sexual orientation, gender identity, sex characteristics" are not prohibited as grounds of discrimination. In addition, even though it is problematic in terms of the criminal law systematics, the phrase: "or similar reasons" which gains importance in terms of showing the approach of the legislator existed in the article before 13.03.2014, however it was removed with the amendment made on this date. According to the principle of "no punishment without law" although the phrase "or similar reasons" is problematic, just the deterrent effect of its presence is important for HIV+ persons and LGBTI+ persons.

Although this article on Discrimination has emerged with the claim of preventing discrimination, while shaping the choice of what is discrimination and what is not according to the preferences of pre-modern legal systems, it essentially evolves to a level that discriminates and as a result, excludes discrimination on account of HIV status and SOGIECS.

Another article that is important in terms of the right to privacy is undoubtedly Article 134 on "Violation of Privacy". According to this article "Any person who violates the privacy of another person's personal life shall be sentenced to a penalty of imprisonment for a term of one month to three years." The health status of the persons is a part of the private life and this is a legal element adopted in the light of the decision of individual applications of the European Convention on Human Rights and Constitutional Court in Turkey. Likewise, SOGIECS are also elements of their private lives. In this case, the transmission of information regarding the HIV status of the persons or SOGIECS to third parties by the informant will be considered as a crime under this article. However, this protection cannot provide complete protection. For example, as it is addressed in detail in the research on health legislation, it is seen that the policy does not exist in terms of lab staff or employees of organizations that have the authority to collect and store blood. Legal regulations on this subject have a general content, subsidiary legislation does not show the existence of the policy and even they do not have a specific content. There is no policy observed regarding regulations

on who can access the health data electronic system where the health information is processed, the measures taken for the security of the data given in this system, regulations on which method to be used for ensuring the staff not to see the reasons of refusal although they can view the refusal to bloodletting. This situation narrows the application area of Article 134 in terms of individuals.

Considering that the penal code lacks an anti-discrimination policy and is even selective between forms of discrimination, and the provisions in other special laws do not regulate in detail how healthcare staff will comply with the privacy of data while having access to specific health-related information, It is observed that the penal code, which does not have such content under any circumstances, does not contain a holistic protection.

On the other hand, apart from its existence in the law, the perspectives of the judges who will enforce the penal code and the prosecutors as an element shape the enforcement. However, in practice, private life is perceived as limited and the discrimination approach is interpreted in parallel with the norms prevalent in the society.

At this point, it is necessary to briefly address the application of Article 86 of the Turkish Penal Code. As it is known, the issue of if the crime of "intentional injury" has been committed by HIV-positive persons who have unprotected sexual intercourse and who do not reveal their status to the person with whom they have sexual intercourse is a current human rights issue. Judicial decisions in this direction are the main factor keeping the issue up to date. As it is known, penal codes should give a clear message to persons about which actions may encounter which consequences. In this respect, the threat of punishment against HIV-positive persons who have unprotected sexual intercourse emerges as a practice that challenges the principle of legality in crime and that cause various rights violations against the person who is forced to share their health status. Due to the right to respect for private life, health status is a featured personal data and cannot be shared without the consent of the person. On the other hand, from the perspective of the person who is thought to be HIV negative, an adult person needs to know the consequences and take responsibility if they have unprotected sex. Considering this situation, placing the only responsibility of

protection on HIV-positive person undermines the fairness character of criminal proceedings, which requires addressing an equal process.

In addition to these, the perception of the issue as only a crime by states without taking any steps to transform this aspect of the social environment that leads to stigmatization, exclusion and even violence for those living with HIV reveals a lack of policy in terms of criminal law. In an environment where prejudices against HIV and the human rights of those living with HIV are extremely strong, forcing a person to disclose their status during sexual intercourse may expose them to the risk of violence. This risk of violence may be higher on the basis of gender - for women, for example. Such a penal sanction can also lead to abstaining from sexual intercourse and inability to exercise their sexual rights.

In summary, if persons share their HIV status during their sexual practices, it will be more clearly understood that the problem is multidimensional, considering that they may face risks to the privacy, physical integrity and safety of their personal information with the impact of the social environment mentioned above. Ideally, the adoption of a human rights legislative and policy framework protecting HIV-positive persons, in order to create an environment where persons can freely share their HIV status if they wish. However; Prevention and protection methods such as condoms, PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis) should be expanded.

In conclusion, it is not possible to say that the Penal Code includes a protection guaranteeing the right of LGBTI+ persons living with HIV in respecting their private life and ensuring them not be subjected to discrimination or hate crimes.

### **3. Labor Law (Published in Official Gazette No. 25134 on 10.06.2003)**

As the data of 2019 Judicial Statistics published by the Ministry of Justice<sup>9</sup> shows, 10 percent of the trials in 2018 took place in labor courts. Labor court are referred in the law regarding the establishment of these courts as the courts which are obliged to solve disputes relating to private law between Social Security Institution and Turkish Employ-

<sup>9</sup> See. <http://www.adlisicil.adalet.gov.tr/Resimler/SayfaDokuman/1982019170455istatistik2018.pdf>, p. 155

ment Agency as well as the trials of seaman<sup>10</sup>, journalists, employees subjected to Labor Law and the ones fulfilling the obligation of service in line with the relevant articles of the Turkish Code of Obligations. Therefore, the fact that a court assigned to solve disputes arising from these laws resolves 10% of all cases, makes it a key element in quantitative terms. This clearly shows how important the Labor Law's standpoint is in terms of relations between individuals, considering that the majority of the trials taken place in labor courts are cases based on the Labor Law.

According to the research published by the Disk-Genel İş/ Public Services Employees Union of Turkey, considering that the private sector has a dominant share of 87% among all sectors, the significance of the Labor Law becomes more evident.<sup>11</sup>

The most important article of the Labor Law in terms of our field of study is undoubtedly the Article 5 on "Principle of Equal Treatment". The first paragraph of this article "no discrimination based on language, race, sex, political opinion, philosophical belief, religion and sect or similar ground is permissible in the employment relationship" was amended on 06.02.2014 into: "no discrimination based on language, race, color, sex, disability status, political opinion, philosophical belief, religion and sect or similar ground is permissible in the employment relationship"

Therefore, it is seen that the motives listed in the article gain importance in terms of policy preferences of lawmakers. However, apart from Article 122 of the Turkish Penal Code, it can be thought that the phrase "or similar" in this article can provide legal guarantee against the discrimination that HIV positive and LGBTI+ persons may face. However, this provides an incomplete protection. If such discrimination is identified, the employer will pay the employee compensation up to four months salary. It is clear that this does not provide sufficient protection. In addition, the law should clearly state "health status, sexual orientation, gender identity and sex characteristics" as categories protected against discrimination.

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<sup>10</sup> According to the Article 2/B of the Law No. 854, "seaman" is the captain, officer and the sailors as well as the other persons working in the ship under a labour contract. This legal definition maintained in the analysis.

<sup>11</sup> See. <https://www.genel-is.org.tr/kamu-istihdam-raporu,2,11140#.Xtoh354zaqQ>

#### 4. Law on Misdemeanors (Published in Official Gazette No. 25772 on 31.03.2005)

While the law was regulated as a part of the former Turkish Penal Code No. 765, it was regulated as a separate law from the Turkish Penal Code as a result of the legislative activity in 2005 and the imposing imprisonment against misdemeanor was terminated and only financial sanctions were applied. In addition, since no sanction was stipulated to deprive the person of liberty, it was ensured that the sanction was decided by the authorized officials. Thus, the role of criminal proceedings in the process of imposing administrative sanctions for misdemeanor was limited to examining objections to administrative fines.

There is no content in the general principles of misdemeanors regarding the protection of private life or the sanctions on discriminatory treatment. In case of hate, discriminatory treatment must be included in the Penal Code. However, in line with the Penal Code, the Misdemeanor Law does not contain any content related to discrimination against HIV status.

### E. OTHER LAWS

#### 1. Law on Human Rights and Equality Institution of Turkey (Published in Official Gazette No. 29690 on 20.04.2016) :

The preparation stage of Law has brought a very interesting process in terms of the human rights movement in Turkey; it has announced its draft recommendations for the content of the civil society law to the public. The purpose of the law is provided in the Article 1 as "***to protect and improve human rights on the basis of human dignity, to ensure the right of individuals to be treated equally, to prevent discrimination against the enjoyment of legally recognized rights and freedoms while acting in line with these principles, to effectively combat torture and ill-treatment and to fulfill the duty of the national prevention mechanism in this regard.***"

Equality Institutions have a practical and symbolic importance in terms of preventing discrimination against HIV-positive and LGBTI+ persons on account of their HIV status and SOGIESC. Especially the National Prevention Mechanism which is described in Article 2 as a body "***con-***

*ducting regular visits to places where persons are deprived of their liberty within the framework of the Optional Protocol to the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*" has been a promising development regarding the implementation of the law. Indeed, the law stipulated the establishment of a body called as "Human Rights and Equality Institution of Turkey" which can evaluate individual applications to be made to regarding the allegations of human rights violations. The duties of the Institution within the framework of Article 11 of the Law is provided as "*to provide decisions on the ex officio investigations regarding the applications made on the violations of the prohibition of discrimination and on violations of human rights or the prohibition of discrimination, to conclude the reconciliation process when necessary regarding these applications, to decide on the administrative sanctions stipulated in this Law regarding violations of the prohibition of discrimination*". Therefore the law, as well as the Institution, has a very important position as not only it determines the violation of rights, but also it decides on an administrative sanction, namely a fine.

How discrimination is defined within gains importance. Clause 1 of the Article 3 of the law on "*equal protection and non-discrimination*" consists a provision as: "*Everyone is equal in the enjoyment of legally recognized rights and freedoms*" whereas Clause 2 of the Article 3 of the law on consists a provision as: "*Within the scope of this Law, all sorts of discrimination based on gender, ethnicity, skin color, language, religion, beliefs, philosophical and political views, national origin, wealth, birth status, marital status, medical conditions, disability, and age are prohibited*".

HIV status is one of characteristics listed limitedly as the ones to be protected against discrimination within the scope of the "medical conditions" provided in the second paragraph of Article 3. The fact that the Institution avoids investigating the applications regarding sexual orientation, gender identity and sex characteristics because these categories are not specified in the Article of 3 of the law indicates that the Institution interprets the law in a restricting and literal manner in terms of human rights principles. Despite this, the phrase "medical condition" in the law reveals the importance of the law for HIV-positive persons.

On the other hand, the fact that only one of the eleven members of the Institution is a woman leaves the public with a question mark on their heads in terms of implementation of an egalitarian policy.

It is not possible to understand the opinions of the Institution regarding the discrimination faced by HIV-positive persons in the decisions published on its website. On the other hand, the presence of HIV/AIDS-related cases in "Combat Against Discrimination- 2018 Report"<sup>12</sup>, which is the most recent report published on the website of the institution, indicates that the institutional policy, which is against the universal values regarding discrimination on account of SOGIESC, can be positive on HIV/AIDS.

## **2. Law on Ombudsman Institution (Published in: Official Gazette No. 28338 on 29.06.2012) :**

The purpose of the law is provided in Article 1 of the law on Objectives as "*to examine, investigate, and submit recommendations concerning all sorts of acts and actions as well as attitudes and behaviors of the Administration within the framework of an understanding of human rights-based justice and legality and conformity with principles of fairness, through creating an independent and effective mechanism of complaint concerning the public services*". Similar to the debates on Law on Human Rights and Equality Institution of Turkey, this law has been closely followed due to its clear references to human rights in the Article 1: Objectives and due to the functionality of the Institution as can be seen in the other countries examples.

There is a chief auditor and five auditors in the Institution; only one of them is female.

As a result of the analysis made by using the keywords "HIV" or "AIDS" on the search engine provided on the website of the Institution regarding the decisions of the Institution; it is observed that there is no decision taken in that regard.

However, after the establishment law of the Institution is analyzed, it can be said that although there is a general reference to human rights, it does not have a clear-cut content that should be carried by a policy-making law. As such, it is controversial whether it is functional in accessing human rights by HIV+ persons. The decisions made by the

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<sup>12</sup> For more information. See. [https://www.tihek.gov.tr/upload/file\\_editor/2019/2018\\_ayr%C4%B1mc%C4%B1l%C4%B1kla\\_m%C3%BCcadile\\_raporu.pdf](https://www.tihek.gov.tr/upload/file_editor/2019/2018_ayr%C4%B1mc%C4%B1l%C4%B1kla_m%C3%BCcadile_raporu.pdf)

auditors on LGBTI+ issues and the public statements made by the chief auditor regarding LGBTI+ persons and the Istanbul Convention are also far from universal human rights principles.

### **3. Law on the Protection of Personal Data (Published in Official Gazette No. 29677 on 07.04.2016) :**

Data security, within the scope of the right to respect for private life, is an issue relatively new in Turkey, which is especially raised by the regulations in the European Union. As a result, the Law on Protection of Personal Data has entered into force. It is very important that policies regarding the protection of human rights are provided by a law, not by subsidiary legislation. However, some provisions in other laws, such as gaps in healthcare legislation regarding the access of third parties to the information collected regarding the individuals, can create precarious gaps in the protection area of this law, known as KVKK.

KVKK explains its purpose in its Article 1 as “***to protect fundamental rights and freedoms of people, particularly the right to privacy, with respect to processing of personal data and to set forth obligations, principles and procedures which shall be binding upon natural or legal persons who process personal data***”. It provides two types of personal data: personal data of general nature and personal data of special nature. It defines personal data as “***all the information relating to an identified or identifiable natural person***”; and it defines the framework of personal data of special nature as “***personal data relating to the race, ethnic origin, political opinion, philosophical belief, religion, sect or other belief, clothing, membership to associations, foundations or trade-unions, health, sexual life, convictions and security measures, and the biometric and genetic data***”.

In the context of “health data” the HIV status of individuals is classified as personal data of special nature within the scope of the law. This leads HIV status to be in a more protected area; since according to the law, such information cannot be processed without explicit consent.

However, the law has provided an exception in the conditions for processing of personal data of special nature, In the paragraph 3 of Article 6 it is stated: “***Personal data, excluding those relating to health and sexual life, listed in the first paragraph may be processed without seeking explicit***

**consent of the data subject, in the cases provided for by laws. Personal data relating to health and sexual life may only be processed, without seeking explicit consent of the data subject, by any person or authorized public institutions and organizations that have confidentiality obligation, for the purposes of protection of public health, operation of preventive medicine, medical diagnosis, treatment and nursing services, planning and management of health-care services as well as their financing".** This leads HIV status to be in rather unprotected area in the context of health data. In other words, while health data is defined as a data of special nature on the one hand, the conditions, in which this data can be processed without even seeking consent, are created.

Within the scope of the exception, HIV status is considered in a wide range in the context of health data, the party is not clearly addressed and the sanctions against the actions that may violate the confidentiality of the data are not explicitly imposed and excluded from the protection area.

## F. SUBSIDIARY LEGISLATION

### 1. Turkish Medical Deontology Statute (Published in Official Gazette No. 10436 on 19.02.1960):

The name of this regulation, which was prepared in order to include the values and ethical codes that healthcare professionals are obliged to abide by in their professions, is "Nizamname-Statute"; since it was based on the Law on the Turkish Medical Association prepared in 1953 and published in 1960. It is a document that has not undergone any amendments after it enters into force.

It reflects the perspective of the period since it does not include the developments regarding human rights and rights of the patients over the past sixty years since it was written in 1960. On the other hand, it is also important in terms of giving an idea about the characteristics of today's regulations by showing the similarities between the approach of the 1960s and the approach of the 2000s.

In the Article 1, it is stated that the statute consists of the conditions that physicians and dentists are deontologically obliged to comply

with, and between the Article 13 and 36, the patient-doctor relations are determined.

In the Article 2 of the statute, “**Physicians and dentists are obliged to show the utmost attention and care in terms of examination and treatment; regardless of the gender, race, nationality, religion and sect, moral thoughts, character and personality, social level, status and political opinion of the patient**”. This is a provision prohibiting discrimination but is limited as it just lists only certain forms of discrimination.

Article 4 of the statute provides the boundaries regarding the privacy of patients as: “**Physicians and dentists cannot disclose the secrets of their profession and art, unless there is a legal obligation. In cases presented at medical meetings or mentioned in publications, the identity of the patient cannot be explained.**” Whereas Article 18 of the statute provides the prohibition to refuse providing treatment to a patient unless there is a professional or personal reason behind: “**Physicians and dentists may refuse to look after the patient for professional or personal reasons, except in cases of emergency assistance, official or humanitarian duties**”.

## 2. Regulation on Community Health Center and Affiliated Units (Published in Official Gazette No. 29258 on 05.02.2015):

This regulation covers the physical and technical infrastructure, duties and powers of community health centers and their affiliated units, and the relations and cooperation with other institutions and organizations. The Article 4 on Definitions specifically includes HIV as “**Infection control unit: The affiliated unit of the public health center that carries out diagnosis, screening, follow-up, training and defined treatment activities for infectious diseases, especially transmittable diseases such as tuberculosis, HIV and syphilis.**”

The duties of the community health centers are listed as “**infectious diseases, immunization and epidemic control, social service studies, in-service trainings**”. While doing these, according to the regulation, the centers shall “**comply with the principles of protecting the rights of patients and staff and of maintaining personal privacy**” while conducting “**monitoring and evaluation studies**” and it accomplish its mission of “**ensuring that studies on rights of patients are carried out and to be monitored and evaluated**”.

Although it does not provide a unit-level sub-task definition for HIV-positive persons, it can be inferred from the nature and scope of the regulation that the duties of Community Health Centers covering infectious diseases, immunization and epidemic control include also HIV.

When the regulation is evaluated in a holistic manner, although the HIV screening, monitoring and training mission is included in the implementation of the studies on rights of the patients and in the definition of duties of the infection control unit in particular, it is seen that it is refrained from defining what kind of rights are these or from providing detailed determinations about the rules to be followed by the staff while performing their duties.

For example, the duties of Data Preparation and Control Operator are specified in Article 60 of the regulation as "**to electronically store the data produced in or sent to the community health center and to check the data**". However, there is no provision in the regulation regarding the restriction of access to personal health data and to ensure that the data is not transferred; which has been discussed a lot after the KVKK came into force.

Therefore, the regulation does not include a policy regarding the respect for the privacy rights of HIV-positive persons.

### **3. Patient Rights Regulation (Published in Official Gazette No. 23420 on 01.08.1998)**

Considering that one of the most visible areas of private law violations in terms of HIV-positive persons is the violation of the right to privacy that leads to discrimination, the protective umbrella of the Patient Rights Regulation is of great importance. The fact that the occasional unintentional learning of health information by a third-party causes a series of violations of rights from employment to housing, access to goods and services, and access to healthcare services except from HIV-related ones increases this importance. While the Article 1 of the regulation on "Purpose" refers to international conventions and the Constitution, it interprets the concept of rights of patients not only in terms of access to health but as protection from violations of rights in general.

Article 5 on “Principles” emphasizes the right of individuals to develop spiritual well-being and the individual’s right to have their spiritual needs met. When the decisions of Constitutional Court, which is part of the Council of Europe system in terms of Turkey, are analyzed; the emphasis is on the spiritual well-being in the applications regarding violation of obligations to respect for private life. On the other hand, in this article, it is stated, *“in the provision of healthcare services, the differences of the patients such as race, language, religion and sect, gender, political opinion, philosophical belief, economic and social status and other differences cannot be taken into account. Healthcare services are planned and organized in a way that everyone can easily access”*, and then it is stated that *“The privacy of the patient’s private life and family life cannot be interfered, except for the conditions permitted by law and medical requirements”*. This regulation, which is a protective document on a theoretical level, paves the way to the practices that may mean violation of private life in reference to the law. Although such restrictions are possible that narrowing down the field of rights of individuals, the fact that this situation is contented with a general reference without listing all, appears as a factor that challenges the guarantees.

Article 16 on “Reviewing the Records” it is stated, *“the patients can review the file and records with information about their health status, directly or through their representatives or legal representatives and can obtain a copy. These records are only visible to those directly related to the patients’ treatment.”* On the other hand, the fact that there is no guarantee that protects the groups who are likely to be violated by their legal representatives and who are “those directly related to the patients’ treatment” is not explained in the Article 4 of the regulation on “Definitions”; leads the hesitation about who can access the HIV status-related information of persons living with HIV and it shows the deficiencies regarding the policy. In Article 17 on Prohibition of Providing Information, it is stated that *“The persons may request that the information on their medical condition not to be shared with themselves, their relatives or no one else. In this case, the written request of the person is required.”* This means that the relatives’ access to information may be restricted. However, it is unclear which sanctions will be imposed in case of violation of this request. The method to be followed and the scope of the exception to be applied in terms of HIV-positive individuals, who are minors or who

are not sane temporarily, are uncertain. This is also the case with regard to Article 23 on “Confidentiality of Information” stating that “***Disclosure of information without legally and morally valid and just reason that are likely to harm the patient also requires the legal and criminal liability of the staff and other persons.***” Although this phrase provides protection, criminal liability already requires a legal regulation and there is no clear protection provided in the Turkish Penal Code analyzed above. On the other hand, no sanctions are imposed.

In general terms, it can be said that the Patient Rights Regulation is a step forward in terms of human rights in that regard. However, unfortunately, it is not possible to talk about the existence of an effective sanction when comparing the results of non-consensual information sharing with the administrative responsibilities of those who share information. As a matter of fact, since non-consensual information sharing, which is frequently reflected in the reports conducted on this subject, does not have administrative consequences, since Patient Rights Regulation does not contain concrete procedures for effective investigation of these allegations and does not include a separate policy for such cases, this regulation appears as a deficient and ineffectual legislation.

On the other hand, taking into account the experiences of HIV+ persons in bloodletting procedures where their personal information may be viewed by the staff who will take blood; it can be stated that the confidentiality that the regulation claims is not guaranteed.

#### **4. Ministry of Health In-Service Training Regulation (Entered into force on 11/12/2009 with the Approval of the Ministry No. B.10.0.S EG0.72.00.03-010.03/15296)**

The purpose of the regulation is stated in the Article 1 as “***To ensure that the staff of Ministry of Health to get trainings in accordance with the current conditions for obtaining the knowledge, skills and behaviors required by their duties; to determine the goals, principles, planning, implementation and evaluation procedures and principles of in-service trainings and other issues in order to increase their productivity and prepare them for higher positions while ensuring them to gain the sense of responsibility.***” It gains importance in that it is directly for healthcare staff and it includes the

goals and principles of in-service trainings; since one of the factors that determine the attitude of the practitioners is the internal training process, although the general legislation on health includes some criteria.

There are five separate sessions in in-service trainings. These are candidacy, adaptation to changes, refreshing of information, preparation for higher-level posts and training of trainers. Although it is not possible to analyze the content of the training curriculum, the Article 5 on the Objectives of In-Service Trainings and Article 6 on Principles set out general criteria. These criteria do not refer to fundamental human rights in any way. It may be necessary not to expect topics such as the protection of the right to privacy and access to the right to health to be listed among the principles and objectives. However, the sub clauses specified as objectives such as "*to provide trainings that will ensure full and timely access of services for recipients*"; "*to ensure the training of staff by raising their knowledge and efficiency, to maximize their interest in service and to prepare them for higher-level position*" or the sub clauses specified as principles such as "*preparing these training based on plans and programs in accordance with national development goals and in line with the aims, duties, authorities, responsibilities and needs of the Ministry*"; are such clauses that can easily include inferences that prevent discrimination against HIV-positive persons.

## 5. Regulation on the Principles of Surveillance and Control of Communicable Diseases (Published in the Official Gazette No. 26537 on 30.05.2007)

Article 4 of the Regulation on Definitions provides the definition of Communicable Diseases Whose Notification Are Compulsory and provides the list in the ANNEX-1, where "*HIV Infection/AIDS (Acquired Immunodeficiency Syndrome)*" took place in the 30rd place in the list of ANNEX-1. Therefore, this regulation is included in our analysis. In this regulation, HIV status is both included as communicable disease and as of which notification is compulsory. Article 9 of the regulation on compulsory notification stipulates a flow system by the Ministry. However, the course of this flow system is not provided in public documents. On the other hand, all public institutions and organizations and real or legal persons are obliged to report the communicable diseases whose notifi-

cation are compulsory to the local health unit, and the local health unit is obliged to report this situation to the Ministry. Although it is stated in the following article that data security will be provided by referring to the Law on the Protection of Personal Data-KVKK, however Article 6/3 of KVKK has already provided authorization to the processing of such data. Therefore, the fact that the right to privacy is kept under guarantee cannot be provided by the mentioned article of this regulation. In particular, it is unclear how information will be made private in the internal processes of healthcare providers.

## 6. Communiqué on Healthcare Implementation (SUT) (Published in Official Gazette No. 28597 on 24.03.2013)

This Communiqué is a very comprehensive communiqué published on the basis of the Social Insurance and Universal Health Insurance Law No. 5510, consisting of 370 pages with its annexes, 65 amendments made after its publication, the last of which was dated on 09.05.2020. Its Purpose is provided in the Article 1 as "*Ensuring medically necessary health services to be provided for the persons whose health benefits are met by the Social Security Institution (hereinafter referred to as the Institution) and are defined in the article on Scope; for them to stay healthy, to regain their health in case of sickness, to recover fully or to some extent in case of incapacity as a result of occupational accident, occupational disease, sickness and maternity and determining the principles and procedures of benefiting from health services, travel, allowance and companion expenses financed by the Institution.*" This highly comprehensive communiqué stands out as one of the important documents on access to health, especially when the details such as whether or not to pay or at what rate the payments will be are taken into account.

The Communiqué covers everyone who benefits from general health insurance in accordance with the provisions of Law No. 5510 and other laws.

The communiqué covers tertiary health service providers such as institutions affiliated to the Ministry of Health namely training and research hospitals and private branch training and research hospitals, district polyclinics affiliated to these hospitals, university hospitals and healthcare practice and research centers affiliated to these hospitals, institutes

and district polyclinics, and faculty of dentistry of universities. In addition, the “patients diagnosed with acquired immunodeficiency syndrome” are considered as exceptional without needing the mandatory referral chains when applying to these listed hospital. In other words, the communiqué provides the privilege of applying directly to a tertiary healthcare institution. The phase in the communiqué “Akkiz immün yetmezlik sendromu” is the Turkish version of Acquired Immune Deficiency Syndrome (AIDS), which refers directly to persons diagnosed with HIV. Applying directly to a tertiary health institution is an important opportunity in terms of access to health services.

However, it is understood that the communiqué does not bring an exception for those who cannot benefit from general health insurance. In Article 1.7 on Provisioning Transactions, it is stated that persons with insufficient number of premium payment days or who have premium debt may be invoiced if they are within the exceptions listed in the same article, whereas the ones with communicable disease to be notified are included in this exception. This means that HIV-positive persons to be considered within this exception are guaranteed within the scope of **Regulation on the Principles of Surveillance and Control of Communicable Diseases**.

There are many details in the Communiqué, which is highly technical and which is publicly known since it provides the medicines and tests covered or not covered by the social security institution, regarding which application will be applied in which cases, what kind of treatment expenses will be covered by the institution within the scope of this application.

It should be noted that although there is no restrictive regulation regarding HIV diagnosis and treatment, the communiqué will not automatically show the situation in practice.

## **7. Regulation on Rewarding Inmates and Prisoners (Published in Official Gazette No. 28603 on 30.03.2013)**

An important article in terms of HIV-positive persons in the context of the right to privacy in this regulation on rewarding inmates and prisoners is the Article 15/2 stating that **“the spouse of the inmate or prisoner, who**

***is known to have a blood transmitted or sexually transmitted disease such as hepatitis or HIV, is informed in writing by the healthcare staff***". Here, the way in which HIV status was learned by the prison/ detention facility authorities is suspicious, as well as leaving gaps in who the healthcare staff who can access to this information and informs the spouse in writing is. On the other hand, there is no procedure for obtaining consent while informing the spouse, and non-consenting information transfer creates a lack of protection with regards to the right to privacy. In the following paragraph it is stated that "***a written statement is received from the visitors who come to the institution within the scope of the spouse meeting, stating that they will inform the inmate or prisoner about whether they have a sort of disease listed in the second paragraph***". In other words, while the prison/detention facility has a routine of disclosing the HIV status of the prisoner to the spouse without consent, it leaves the responsibility in the same condition to the spouse. It is very clear that there is discrimination independent of the intention of the institution.

## G. RTÜK's Decisions

Although it is not the direct subject of the research, a few striking examples of how the Radio and Television Supreme Council (RTUK) handles the issue will be shared in the context of this study.

As a result of the keyword search by HIV and AIDS keywords, the expert report based on the RTUK's decision dated on 28.01.2015 is obtained which provides an evaluation stating that; "*In the TV movie adapted from a theater play shot in USA in 1994, AIDS, which was caused by a virus known before as a type of cancer but understood later to be HIV in the following years, spread rapidly among gays in 1980 and caused the death of many gays.*" It is also stated there that "*While the struggle of gay men against AIDS, which is an important health problem, was dramatically brought to the screen in the mentioned movie, the experiences of love and sexual life of gay men, which is difficult to be accepted in the social sphere of life as in many countries of the world have been shown on the screen. This has been evaluated as an issue that leading the feelings of shame of the society and challenging the boundaries of general morality*". This report is presented as the basis for the requirement to impose sanction on the relevant TV channel broadcasting that movie.

In the evaluation on another TV channel where the same movie is broadcasted, RTUK has given an administrative sanction decision on the grounds of such: “*it has been concluded that the movie may negatively affect the younger audience, whose sexual identity is not established, who are not yet aware of the meaning of expressions, repeated frequently, such as homosexuality, homo, gay (clip1-2) and not yet aware of that homosexual tendency is a different behavior pattern (clip3-4-6)*”.

Considering RTUK’s decisions that are not limited to these, it is inferred that the mainstreaming of stereotypes and misinformation that triggers discrimination in the context of both HIV status and sexual orientation and gender identity are easily realized because the rules do not contain anti-discrimination provisions.

## H. CONCLUSION

The rights of HIV-positive persons are human rights. The state should form the norms regarding human rights in line with the laws and should transform them into the parliament’s discourse. This is because the inclusion of regulations on fundamental rights only provided within the rules called subsidiary legislation such as communiqués, statute laws and regulations will both reveal the problem of binding nature and may violate the law, which is the document of forming the norm. For this reason, it is not enough that the perspective on fundamental human rights is vaguely included in the constitutions or in the subsidiary legislation; it should be included in the laws effectively.

As stated in this study, for example, since Article 122 of the Turkish Penal Code prohibits discrimination in terms of some forms rather than in general, for example, not renting a house as a result of hate on account of political opinion is considered as a criminal act, whereas the same act on account of HIV status or SOGIESC is not regulated as a criminal act. This situation shows how difficult it is to implement the Article 10 of the Constitution on equality where there is no legal regulation.

In the analysis conducted for this study, it has been focused on whether or not there is any constitutional and legal protection and whether or not there is any provisions in subsidiary legislation regarding the rights under protection as stated in the following human rights materials: Uni-

versal Declaration of Human Rights, the European Convention on Human Rights, United Nations International Covenant on Economic, Social and Cultural Right, the Constitution of Turkey.

In this context, an analysis has been conducted for this study in the context of some of the fundamental rights listed below.

- Right to dignity
- Right to life
- Right to physical and mental integrity
- Right to respect for private life
- Right to education
- Right to work
- Right to just and favorable conditions of work
- Equality before the law
- Prohibition of discrimination
- Right to social security
- Right to health
- Right to housing
- Right to an effective remedy

As general headings, there are provisions in the Constitution that can be associated with these rights. Article 10 of the Constitution, which guarantees equality before the law, does not explicitly prohibit discrimination, and does not contain all the norms needed in combating discrimination in terms of forms of equality. On the other hand, the exception provision that personal data under the obligation to respect private life can be processed without consent is an element that weakens the effect of the norm. As a matter of fact, health data can be processed without seeking consent by persons or authorized institutions and organizations that are under confidentiality obligation in the context of

KVKK. This expands the protection area in terms of HIV status to such an extent that it cannot be controlled or limited.

Regulations on access to health are relatively inclusive. However, it is not possible to talk about the existence of sufficient legal protection in combating discrimination while receiving health care.

The prevention of access to goods and services on account of HIV status and SOGIESC is not regulated with a sanction in the Turkish Penal Code. However, the same article enumerated a limited number of forms of discrimination and excluded some of them. Therefore, the law does not have a protective nature against the exclusion of the housing rights of HIV+ and LGBTI+ persons such as renting a house and staying in a dormitory.

Article 5 of the Labor Law on equality is also a protective provision for those who are discriminated against on account of their HIV status or SOGIESC in the workplace. In an individual application lodged (2014/19081), the Constitutional Court examined the treatment in the workplace on account of HIV status in the context of the obligation to respect private life in line with the European Court of Human Rights. However, the upper limit of compensation in the Article 5 of the Labor Law (compensation up to four months) is far from being deterrent. In addition, in order to benefit from this protection, a business relation built with the employer is required. On the other hand, this article, which protects the HIV+ or LGBTI+ employee from the discrimination of the employer, does not protect the individual from the discriminatory treatment of their colleagues. Likewise, there is no rule restricting the disclosure of HIV status or SOGIESC in the workplace without consent.

As mentioned above, although the right to respect for private life is defined in the Constitution, there is obvious deficiencies and gaps in the laws. This situation shows itself in the uncertainty about how the state will fulfill its positive obligations both in the exception provisions of the KVKK and in preventing discrimination between individuals. Although the protective provisions in the Turkish Penal Code provide an umbrella in a sense, the field of exception is quite large. As a matter of fact, the various reports published by institutions operating in the field of HIV highlight the deficiencies frequently.

## 10. Living with HIV: Testimonies by the participants

Living with HIV is not only a health condition but also a source of unique stories. The subjects have many experiences, sometimes bad and sometimes good, in these stories. To understand what it is like to live with HIV, it is necessary to create environments where those living with HIV can come out and tell their stories, because what it is like to live with HIV can best be told by the subjects themselves. The hospital processes experienced since the moment of HIV diagnosis, the solidarity built, violations of rights experienced, coming outs and many other details are forming the unique stories of the subjects. To understand these experiences, we asked the participants what HIV means to them as follows:

**KAА:** *"I have built lots of defense mechanisms. I feel stronger after each trauma. I went to Ankara a week after I found out that I am living with HIV. I both learned that I am living with HIV and witnessed to a massacre in Ankara. But I knew one thing, it would strengthen me a lot if I got through them. That is why I was improving my analysis skills. I question and analyze everything too much. This raises the bar for me. I see HIV as my little monster. Sometimes I see it as a weapon. I say, "Come on my monster, go attack them and come back". Sometimes I forget about it, sometimes I neglect it, sometimes I remember, sometimes I speak openly about it and I love doing it. I no longer suffer from living with HIV, but this is an area to struggle. I also know that when I see this power in myself, I will struggle in the field more, but now I do not feel ready to fight, this struggle fully. I have had a process related to HIV. Maybe it was very difficult, maybe I struggled a lot, but I feel so good where I am now finally. I am following the developments about HIV and knowing something about it makes me happy. But I also see a lot of persons who are upset and I want to fight for them. I want everyone to see this and free themselves. I want to reach other persons living with HIV."*

**IAO:** *"I pay attention to my actions and behavior. I limit myself. Social anxiety is a bit tough. I always try to think: this is my identity, but not*

*is my only identity. This is how I overcome my depression. I am not just that: I say to myself. I am struggling by raising my awareness. I hope that all of us can one day be able to come up and share this with everyone without fear. I hope these studies will lead to this. HIV is a condition that teaches me so much. It is like a milestone for me. It raised my awareness. It made me see what I had. It made me realize the value of life. I try to live and fight as best I can as a HIV positive gay in this society. HIV made me hold on to life more.”*

**KEK:** “*I know I cannot handle it. I am a sensitive person. When something happens to me, it affects my whole life. That is why I think and plan ahead and take steps without any problems. Living with HIV was a problem and the way I dealt with it was staying in bed for 2 months, but then meeting someone living with HIV changed my life. We need to reconsider the points that we thought we are conscious about. I want to make HIV more talkable and thinkable rather than to be considered more scary and deadly. Now, instead of saying “persons should not be infected with HIV”, there should be efforts focusing on changing perception. There should be struggle to ensure HIV-positive persons to face no phobia. HIV means nothing to me anymore. I take one medication a day and I remember to take with a notification. My life is very stable.”*

**AAA:** “*There is a period where I really know what HIV is, and there is a period where I cannot access this information. I ignored it as a defense mechanism at that time. For years I said “This is not in my life”. I did not think on this. I have never make a research, ever. Then I let my friends strengthen me. I read foreign sources, attended the trainings, and then I started living with HIV, getting used to it, and now I have the power to think about how to raise the awareness in persons when I am exposed to anything. I am not frustrated anymore. I do not frustrate when I am left with myself, but I try to support someone else when they are exposed. Remember HIV-positive foreign nationals. Conduct studies about them and boost their visibility. I do not think so much about HIV right now. I used to say things like that “it is ruining my life” It does not make much sense for me right now. There is a point where I am against discrimination, but I do not think much individually. I can say that it is something in my life, something I was living together with.”*

**IEY:** “*For the beginning of the process, I really think the right resources were really good at coping with it. The support of close friends, associ-*

*ations and consultants is very important. It is very important to know your HIV status. HIV should not be feared and it is very important to find the right resources. They should not close the page at the first misinformation. Let them investigate it. They should not be afraid. For their own health and for their well-being. HIV gave me a life. I was going to be an actor or be stuck in the private sector. Maybe I could have existed with my closed identity. I would have had an artificial life. HIV wiped out my suspicions. "Would you choose that life again?" If they as I would say, "No, I do not." I met very nice persons. It gives me pleasure. It makes me feel happy.*

**IDI:** "My struggle has changed from time to time. At first, I coped with it having frequent sexual affairs. I was not eating, I was starving with headaches, but I was waiting for sexual partners. Sex was tiring after a while. I traveled a lot in the following periods. Recently, the best thing for me has been to have artistic activities. I was very scared in the beginning. Then I got used to it. Now I do not care. Always there is a solution, I say. I never stop taking my medication. Like an old friend now. I do many things that HIV-negative persons are unable to do by being too lazy to do; it is the same regarding the control. That is why I love to be living with HIV. Someone I consulted told me something: "This is a wake-up call for us". This was a lesson for me. After that, I try not to approach from a moral point. I lived through very tired years. Work five days a week, drink like a fish on the weekend, then find sexual partners. My life was like this and it was not suitable for me. For example, I reduced drinking. I still drink, but when I was in my daily life I noticed that it affected me badly and reduced it. I had a more organized life. I clung to my job. I have traveled more. I am dealing with the help of art. I started to do whatever I always wanted to do. HIV has become something that has stopped a life going downhill. My life has improved with HIV. It made me to back on track. It jolts me out of such a life. This is not a norm. This is just something right for me. Living fast was not for me. I am a grumpy. HIV said "Come on pull yourself together!" and I did."

**IKH:** "I get support from my friends. HIV is something I often forget. I do not take it as a great identity. Something I remember once a day with the pill, I take it and forget. Sometimes I forget that even what the pill is for. Actually, I want to live like this, but sometimes this is prevented. I would not mind much if there were no areas where I had problems or areas I could not express it. It does not affect me at all in the healthcare dimension."

sion. One medicine, check every six months. But encounters and phobia bother me. It is part of my life. It does not affect me much. It happens mostly when there is a second person affects me negatively. I think such studies on HIV are very valuable. I think such studies done with subjects are valuable. Lets talk about us a bit now. It is good to return to yourself and recall your own process. You are evolving from such a lonely phase into such a powerful phase. This is very nice."

**İAE:** "HIV is just one of the millions parts of me. Considering this, there is nothing left to struggle. I ignore it excessively. For me, HIV is a virus that wants to live in my body, does not want to go outside, and is happy in my cells. I wish we could accept ourselves more and have raised up our voices more. Because to break a prejudice, the subject must first be able to speak up. I guess this is my biggest wish. To be able to talk more."

**İÇB:** "The more I am open, the more liberated I feel. The more I tell, the more I feel that I am freed from my burdens. Self-expression is very empowering. I see coming out as a favor for myself. I want prejudices to end as soon as possible. I think that the power with which they usurped my life should not be in their hands and this power is very dangerous. The dimensions of prejudice can be terrible. Every word we say, every action we do can affect a person's life enormously. That is why it is necessary to think a little more before talk and not talk about on the topics we do not know."

**İDE:** "Throw shade and solidarity are my biggest weapons. It was difficult before I included the persons I could speak to. Now we are coping with all the madness together dividing it into three and four. These two are enough for me. HIV is something I did not know I have kinda phobia before I got infected. On the other hand, it is something that makes my life beautiful. I think the things I learned right from HIV policy are very valuable and empowering. It has been a good litmus test for me. To hold this on my hand makes me happy, frankly. I think that what is good for me, the advantage of throwing shade are something privileged. Unfortunately, not everyone has this opportunity. I hope everyone can reach the opportunity of being shade thrower and solidarity."