Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

FINAL Report
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

Vilnius, September, 2009

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## Glossary of acronyms and definitions

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People Living with HIV/AIDS</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
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<tr>
<td>CSW</td>
<td>Commercial Sex Worker</td>
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<tr>
<td>IDU</td>
<td>Injecting Drug User</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infections</td>
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<tr>
<td>ART</td>
<td>Anti-Retroviral Treatment</td>
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<tr>
<td>LAC</td>
<td>Lithuanian AIDS Centre</td>
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<tr>
<td>EMCDDA</td>
<td>European Monitoring Centre for Drugs and Drug Addiction</td>
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<tr>
<td>CRIS</td>
<td>The Country Response Information System</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>NGO</td>
<td>Non-governmental Organization</td>
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</table>

**STIGMA**

refers to all unfavourable attitudes and beliefs directed toward people living with HIV (PLHIV) or those perceived to be infected, as well as significant others and loved ones, close associates, social groups and communities.

**DISCRIMINATION**

Discrimination consists of actions or omissions that are derived from stigma and directed towards those individuals who are stigmatized.

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1 Adapted from UNAIDS, UNICEF, AIDS info (http://aidsinfo.nih.gov/Glossary) and GMHC (http://www.gmhc.org/health/glossary2.html)

Background

This report describes findings from the research initiative sponsored by the UNDP Regional Centre for Europe and the Commonwealth of Independent States (CIS) that aims to identify barriers to the full social integration of people living with HIV (PLHIV). This study focuses primarily on access to healthcare, education and employment.

This research began as a pilot study in Estonia and in the Kaliningrad region of the Russian Federation, which were selected because they have the highest HIV infection rates in the region.

The second stage of the study was simultaneously conducted in Georgia, Russia, Turkey, Uzbekistan and Ukraine.

This report contains study findings from Lithuania. The goal of this study was to assess the ways that PLHIV and service providers view PLHIV’s access to medical services, education and employment in Lithuania.

Study objectives:

- To provide insight into the experiences of social vulnerability among PLHIV and identify barriers to the social integration of PLHIV.
- To assess the attitudes and practices of institutional representatives (from the health, educational and labour market sectors) working with PLHIV.
- To establish policy recommendations and implications for advocacy that will support the national government in eliminating discrimination and promoting the full integration of PLHIV, particularly regarding access to healthcare, education and employment.

To achieve the objectives of this study include the following steps:

1. Desk Review

The “desk review” was an intensive literature search, review, and a summary of all relevant documents concerning Ukraine’s current HIV policies and the provision of services and programs to protect the well-being of PLHIV. This includes, for example, epidemiological estimates of HIV prevalence and incidence rates, key policy or public health documents, and local initiatives to promote the well-being and human rights of PLHIV.

2. Community mapping

The purpose of community mapping was to obtain a geographic awareness of the physical communities and environmental spaces that PLHIV and populations at higher risk inhabit or frequent, learn about size, density, visibility and accessibility of the target populations, and develop a sampling plan based on first-hand knowledge of the community.

3. Narratives of PLHIV from in-depth interviews

The purpose of the individual interviews was to obtain first-person accounts from PLHIV about their experiences of discrimination, stigma, and vulnerability in society. Analysing these first-person narratives allowed for a deeper understanding of the ways by which PLHIV are excluded from full participation in society, and these accounts were used to create a broad taxonomy of indicators of vulnerability among PLHIV.
4. Focus groups with institutional representatives.

The purpose of conducting focus groups was to obtain narrative accounts from representative members of “mirror” organizations that work with PLHIV (government officials, healthcare providers, employers, colleagues at work, teachers, parents, schoolmates, NGOs, the police, and others). These narratives assessed representatives’ attitudes towards and relationships with PLHIV, as well as their perceptions of policies and programs addressing AIDS in the local society.

5. Roundtable

The purpose of the roundtable is to report preliminary findings from the in-depth interviews and focus groups to community constituents and policy-makers, engage these audience members in a discussion about the preliminary findings, and document the opinions and comments raised by audience members. The roundtable is both a research activity and a dissemination activity.

A more detailed description of the survey methodology can be found in Chapter II: Methodology.
Executive summary

The report “Vulnerability Assessment of People Living with HIV (PLHIV) in Lithuania” is a part of series of comprehensive qualitative studies conducted by the UNDP Regional Centre for Europe and the Commonwealth of Independent States (CIS) in selected countries, including Ukraine, Georgia, Russia, Turkey, Ukraine, and Uzbekistan. The overarching aim of this research is to identify existing barriers to the full integration of PLHIV in each of these Eastern European or CIS societies. The studies focus primarily on access to health care, education and employment.

The report is based on interviews conducted with PLHIV in Lithuania and focus group discussions with Lithuanian representatives of the education, health care, employment sectors and NGOs working in HIV- and AIDS-related fields.

This qualitative study was conducted by the Vilnius Institute of Hygiene under the Ministry of Health during March and September 2009. Researchers used in-depth interviews and focus group techniques to outline the problems of stigma and discrimination towards PLHIV and to identify barriers that prevent PLHIV from achieving full integration in society. The study used qualitative research methods because of their suitability for arriving at an in-depth understanding of the participants' experiences, including their potential receptiveness to future HIV-related initiatives.

According to the survey objective, we have selected two types of respondents:

- People living with HIV (PLHIV)
- “Mirror institution” representatives including government officials, health care providers (doctors, nurses), social workers, educators (teachers, psychologists), employers, NGOs and others.

Altogether, this study included 20 in-depth interviews with PLHIV, 3 focus group discussions, and 1 roundtable discussion.

The results of the analysis of qualitative data revealed the following experiences of PLHIV in different environments and interactions:

Experiences of PLHIV in the personal environment

- An HIV-positive person tries to “tame” their life situation that has been determined by the HIV-positive diagnosis. The individual’s realization of the diagnosed HIV passes the following two phases – an emotional shock and psychological adaptation to the health status caused by the diagnosis. The person infected with HIV reflects on his or her current personal life and future after the diagnosis of HIV, re-evaluates their life values and feels like a leper or condemned person in society as a result of the existing negative attitudes.

- Societal attitudes and reactions to PLHIV and HIV/AIDS problems are related to awareness and negative conceptions formed over time as a result of ignorance and lack of awareness, which is why HIV-positive persons are identified with risk groups, avoiding to view this disease from two aspects – as a social problem and as a disease which must be treated and prevented. The lack of accurate information about HIV in society causes stereotypical tension linked to the fears of society of becoming infected and experiencing a quick and fatal end.

- The openness of an HIV-positive person to his or her close environment unblocks and cleanses relationships/communication between close family members and
friends. The loss of friends and relatives and separation of partners is often experienced as a result of their negative viewpoints and stereotypes.

- While experiencing the compassion and pity of their environment, PLHIV feel emotional discomfort because they understand the fears of people surrounding them that are covered up with goodwill and other behavioural strategies. This situation results in the individual's gradual exclusion in his or her work environment and outside of it in the formal social networks that are relevant work-wise for a person living with HIV.

- When assuming responsibility for their own health and the health of people surrounding them, PLHIV empower themselves to continual and systematic care of oneself by giving up their harmful lifestyle and harmful habits which have caused their HIV-positive diagnosis, being attentive in taking medicines, eating nourishing food, and avoiding being in environments where alcohol and drugs are used because being intoxicated may lead to negative consequences for their own health and the health of others.

- Having stereotypical attitudes, society does not enable itself to change the, and often the opinion still prevails that HIV is a problem of “others” even though those “others” are members of the society which all of us live in. Thus, the realization process is slow and is related to new information about the number of new HIV-positive cases provided by the media or reading occasional information about negative examples of PLHIV.

- Having realised the impact of the HIV diagnosis on his or her future life and health, an HIV-positive person loses the joy of life, understand the limitations of his or her life, and “imprisons” him or herself in psychological and cognitive “captivity” by controlling his or her talking and behaviour in their environment. This double psychological tension suffered by a person living with HIV deprives him or her of the ability to feel comfort in comfort, causing depression and, in some cases, even resulting in the decision to choose to end one’s life upon the appearance of associated health complications.
Experiences of PLHIV in the educational system

- PLHIV experience a fear of being rejected after informing others about his or her HIV diagnosis because they do not trust the ability of their environment to maintain confidentiality and are afraid of negative attitudes which manifest themselves in exceptional attention towards PLHIV, which is not always positive. This is why PLHIV make a decision to inform their environment only in exceptional cases according to the need and intensity of communication with specific persons.

- Communication with a medical specialist and psychologist according to their needs is vital for PLHIV. A medical specialist in the educational system should not only perform the role of a consultant, but also engage in educational activity working with the school’s teaching community. Informed teachers would not create preconditions for stereotypes to become entrenched and would take into account the learning possibilities of HIV-positive students based on their health status. However, neither special learning conditions should be created nor specific attention be paid to PLHIV because this “exceptionalness” strategy would cause the social exclusion of PLHIV in educational institutions.

- Due to the lack of information, teachers working in the educational system are categorical and adhere to stereotypes not only in interacting with PLHIV but also with people with any contagious or chronic disease. Ignorance triggers psychological tension and inadequate reactions projected onto people living with this disease or their close family members.

- In educational and training institutions, there is a need for moral transcendence from ignorance, distancing, disassociation, fears and tensions caused by not knowing, insecurity and distrust, categoricalness, secrecy, condemnation, lack of awareness, creation of stereotypes based on a diagnosis and lack of knowledge on the maintenance of personal dignity, goodwill, tolerance, equality, the maintenance of confidentiality, the self-empowerment to expand and deepen one’s knowledge, the dissemination of information, and the recognition of an individual as the highest value.

- Having found out the information about PLHIV, specialists working in the educational system experience pity but they accept it as a statistical fact, a new HIV case, and they accept it in a universal human sense, having no experience in encountering an HIV-positive person.

- Specialists working in the educational system lack accurate and objective information about HIV/AIDS, which causes their anxiety surrounding a direct encounter with PLHIV – they would not know how to react and behave or what to say in such a situation. Therefore, not only general information about HIV/AIDS is necessary, but also information about the experiences of PLHIV (both positive and negative) is necessary, and this would be the first important step in overcoming stereotypical barriers and understanding that PLHIV are not a diagnosis but people with needs, feelings, and specific competences.

- Information provided to students in schools is short-term, general, and occasional, and lacks continuity and a systematic approach in being directed at the age group of pupils and acquiring of new social experiences. There is a lack of information in the school community, i.e. teachers, parents, and school administration.

- Students of all age groups require education in universal values without concentrating specifically on HIV/AIDS-related problems but on tolerance, goodwill, empathy, compassion, sensitiveness, friendliness and other features necessary for dignified and equal communication by presenting experience-related cases of various diseases, disabilities, chronic incurable conditions, etc., which would create preconditions for the development and strengthening of students’ social competence and emotional intelligence, but which would not ignore personal dignity, respect, and self-esteem. While orienting itself exclusively towards students’ achievements, the concept of a school of general education does not enable one to maintain a balance with ethical, value-based, social and civil education.
Schools avoid recognising HIV as an existing reality in society, and there are no systematic discussions held on HIV as a disease but rather as a social problem and issues faced by PLHIV. By ignoring the possibility of an HIV-positive student being in school, they distance themselves from an issue that is relevant for society, thereby possibly creating a situation where upon the revealing of information about an HIV-positive student in school or about HIV-positive parents of a student, an emotional breakdown or even psychological destruction on a school scale would occur, expressed as a mixture of panic, emotional shock, anger, anxiety, and fear resulting in the social exclusion and hostility of and psychological and moral pressure towards the HIV-positive pupil or pupil who has HIV-positive parents.

The exclusion of PLHIV in society and in the school environment is caused by the myths entrenched in society: HIV is an incurable and terminal disease; an HIV-positive person is a representative of a risk group; there is a fear to get or be infected; the HIV-positive person himself or herself is not condemned, but rather his or her behaviour that does not conform to moral norms of society, with the HIV-positive diagnosis the outcome of this kind of unacceptable behaviour.

HIV-positive students should not be separated from HIV-negative ones in the educational/learning process neither inside nor outside the institution. However society relies on negative stereotypes, and there is only psychological protection available, which is the maintenance of confidentiality in the educational institution, because open disclosure of information about the diagnosed HIV creates preconditions for panic in the community of the educational institution where an HIV-positive person (or the student who has HIV-positive parents) studies, resulting first of all in the condemnation of the HIV-positive student or his/her parents (particularly where parents are HIV-positive).

There are no specific restrictions on the selection of a profession by an HIV-positive person; however, he or she must empower himself or herself to protect his or her health and the health of his or her environment and assume responsibility for this. This means knowing that he or she might get injured in the work environment and thus pass the infection to others; an HIV-positive person must make a decision regarding the change of his or her profession. However, this kind of situation cannot be treated categorically and unambiguously because a categorical approach does not integrate one's calling, desire, and freedom of choice as required components in choosing one's profession.

The school environment is in a dilemma regarding the acceptance of PLHIV: on the one hand, the need to communicate with HIV-positive people on an equal footing is well understood; on the other hand, the positive evolution of thought is overwhelmed by the fear of death as a result of the threat of HIV. There are prevention programmes being implemented in schools; however, the monitoring and assessment of the efficiency of these kinds of programmes are not carried out because all programmes are oriented only towards learning achievements, leaving personality, social values and social competence as well as the emotional intelligence of students in the background. The efforts of several pedagogues and other specialists need to be combined for the implementation of an integrated education; however, this requires additional time, efforts and revision of the content of programmes.

Problems of PLHIV in the Lithuanian educational system are caused by the following factors: categoricalness of societal attitudes, impacting the decision of an HIV-positive person to not inform their environment about their diagnosis; the ignoring of the importance of HIV-related problems and passing on of responsibility to “others”, and the orientation in schools towards learning achievements, leaving HIV-related problems in the background; the non-systematic provision of information about HIV / AIDS based on the age of pupils in schools.
Experiences of PLHIV in the labour market

Most frequently employed PLHIV make a decision not to inform their employer and work environment about the HIV-positive diagnosis, because this will result in the loss of their and social exclusion. PLHIV are not inclined to disclose their diagnosis to their employer because in such cases where there is an alternative to choose between two employees, the “healthy” person will be chosen irrespective of his or her other habits, even if they are harmful. The major obstacle on the labour market is the non-awareness and ignorance of employers themselves of the need for knowledge concerning HIV/AIDS.

In the labour market it is not exceptionalness that is important for HIV-positive persons, but equality, i.e. human dignity in the labour market context. Specific laws creating preconditions for HIV-positive people to exercise their rights and guarantees and encouraging employers to hire PLHIV are necessary. Employers must have training on HIV which would enable the development of their tolerance and understanding as a means of preventing social exclusion in the context of the labour market.

Employers are members of society influenced by the stereotypes existing in society concerning PLHIV and obstacles are reflected in the following stereotypes: priority is given not to the competence of PLHIV but to the HIV diagnosis; an employer’s fear and anxiety caused by his or her lack of being informed of the specific problems of HIV result in irrational and negative decisions concerning an HIV-positive employee.

The awareness and accurate knowledge of employers of HIV/AIDS issues is positive active prevention in terms of the social exclusion of PLHIV. This enables an employer to concentrate not on the individual’s HIV diagnosis but on his or her professional qualifications, acquired competences and competence that are a result of his or her work experience.

PLHIV are not inclined to openly discuss their health situation with colleagues or employers because they are afraid of social exclusion and job loss. Individuals who possess a high social status and financial possibilities allocate plentiful financial resources for treatment outside Lithuania, thus maintaining their confidentiality. “Other” HIV-positive people live under psychological stress caused by the diagnosis and physiological ailments, concealing their diagnosis from their environment.

PLHIV should not be restricted in selecting a profession; however precise criteria regarding the possibilities of PLHIV to work in specific professional fields should be defined. This would serve as a basis for the prevention of social exclusion of PLHIV based on objective criteria.

Experiences of PLHIV in the health care system

PLHIV often experience negative health conditions such as excessive sweating, weakness, fatigue, physical and intellectual exhaustion, lack of appetite, vesicular skin rashes, constant sensation of heat, leg pain, long-term depressive states, digestive system disorders, seborrhoea, excretory system disorders, and enlarged lymphatic nodes. The aforementioned symptoms are particularly typical of PLHIV who have had this disease and have been taking antiretroviral medicines for several years. PLHIV who have been diagnosed with the disease for one or two years state that their health status is good – they very rarely get sick with infectious diseases or colds. However, PLHIV suffer from associated diseases which they have had before the HIV-positive diagnosis or which have occurred after the diagnosis.

The participants in the study understand their needs concerning the maintenance of their health but the main barrier in addressing specialists is their poor financial resources or the absence of financial resources. The most relevant consultations for PLHIV are with a family physician, infectologist and odontologist. Maintaining contact with a gynaecologist is very important for HIV-positive women. Due to occurring associated diseases, PLHIV have to visit a cardiologist, oculist and surgeon.
A substantial number of PLHIV do not contact medical specialists and prefer to rely on information and support provided by their friends.

- The low awareness of HIV / AIDS issues among medical specialists causes their fears, anxiety and inadequate emotional reactions and behaviour when coming face-to-face with an HIV-positive person. In these kinds of interactions, medical specialists in health care institutions tend to put labels on PLHIV without adhering to the principles of respect for personal dignity and confidentiality, while PLHIV experience external pressure, moral humiliation, and social and psychological exclusion.

- The health care system has not adapted to the needs of HIV-positive people yet: workloads for physicians in the health care system do not allow for paying greater attention to PLHIV, and there is a need of PLHIV for physician consultations and conversations about problems arising in connection with health, psychological or social issues.

- Health care specialists understand the complexity of the social situation of an HIV-positive person caused by the diagnosis: in the public context, an HIV-positive diagnosis is a “punishment” intended to “punish” an HIV-positive person; therefore, he or she must repent and society does not want to forgive him or her for this.

- Medical specialists are taught about HIV, but stereotypical attitudes often win out over accurate information on HIV. Having encountered an HIV-positive person, physicians or care specialists still often act unprofessionally by humiliating the human dignity of the HIV-positive person and the professional dignity of the professional medical community. The first reaction is often based on the “labels” medical specialists use for PLHIV, labels which have already become a stigma that identify PLHIV with risk groups based on their lifestyle and potential for becoming infected with HIV.

- The stress and emotional discomfort experienced by a physician before, during and after informing the patient about the HIV diagnosis shows that a physician simultaneously experiences multilevel professional stress in the work environment which is difficult to deal with emotionally and psychologically. However in this situation the physician is the person providing information. However in another case, where he or she is unexpectedly caught unprepared by an HIV-positive patient who himself states the fact of HIV infection, the physician experiences stress caused by stereotypes in society.

- A primary problem for PLHIV is access to health care service, because PLHIV do not have social guarantees, even though specific laws, which are ineffective, have been passed. When there is no system for a regulated legal basis in terms of tangible results, assistance provided to PLHIV is often based on a physician’s goodwill. Therefore, regulations are necessary in the health care system so that activities and functions of institutions and specialists would not overlap and that there would be a clear hierarchy based on responsibilities and accountability in working with PLHIV. There is no effective PLHIV support system that exists based on continuity and systematic organisation. The claim of the public at large and individual specialists that there is a lot of information on internet portals is irrational. Unprofessional information may be found not only on Internet portals but also in magazines and newspapers. However, there is a need for an HIV-positive person to receive professional, reliable, and accurate information that is clearly presented.

- The legal base created in Lithuania guarantees confidentiality for PLHIV; however, there may be a gap between the formal obligations to keep confidentiality and the actual observance of this principle in practice in the medical community.

- In Lithuania, antiretroviral treatment is free of charge but a person must have associated diseases treated at his or her expense.

- The obstacles in the programmes being implemented could be linked with the effectiveness's local confinement along with the irregular character of programmes
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

only oriented towards a specific group of people in the absence of continuity and being prolonged; unforeseen problems arising during the implementation of the programme are eliminated at a slow pace; the assistance provided to PLHIV within the framework of the programmes is one-off in character and usually piecemeal; the majority of programmes are implemented only in penitentiary institutions.

**Factors having a positive impact on increasing the level of tolerance concerning PLHIV in society and medical community are the following**

- The need for medical workers to develop social and communication competences, to deepen their knowledge on HIV / AIDS issues, to expand their emotional intelligence; to promote and ensure the systematic provision of information and education on HIV / AIDS and professionalism for different groups of people based on their age, various institutions and the professional medical community by involving experts representing the fields of medicine, public health, psychology, social work and care to carry out educational instruction.

**Experiences of PLHIV in various environments and interactions**

- Because of a low level of income, PLHIV have problems making house payments and purchasing food or clothing. A need arises for PLHIV to receive social support for house-related services and discounts for medicines which may be given provided that PLHIV have a disability. The latter often means making their diagnosis public, which PLHIV try to avoid and are afraid of.

- The demand for psychological support is particularly acute and urgent when a person finds out about his or her HIV-positive diagnosis. In this case, PLHIV need a listener rather than a moralizer, silence rather than targeted questions, sensitivity and empathy rather than instructions on a strategy for life, consulting according to need rather than consulting based on a psychologist’s work schedule.

- Social work services are important when obtaining required documents and providing advice to PLHIV on the alternatives, ways and actual possibilities for dealing with social problems. A social worker helps PLHIV regain emotional strength and provides psychological support.

- In penitentiary institutions, HIV-positive people are isolated by allocating a separate room to them, which has an impact on their psychological exclusion – other people in penitentiary institutions treat them as “different” or “exceptional” in a negative sense. In penitentiaries, there is a lack of physicians, and their workloads are enormous – the number of people who have various diseases is very large, and therefore a physician has no possibility to provide assistance to everyone and in a high-quality manner.

- NGO activities should be carried out through communication and organisation of self-help groups. NGOs are considered to be an intermediary in providing moral and financial support or residential premises to PLHIV. The initiatives of NGOs are important in promoting the establishment of consulting services, telephone hotlines or consulting rooms in towns or villages where PLHIV do not have possibilities to receive consulting and accurate information or to visit medical specialists if there is a need. The problem is not the avoidance of PLHIV to contact medical or other specialists but the lack of specialists who would be able to provide assistance in connection with particular issues.

- PLHIV can help themselves and other HIV-positive people by revealing their experiences, sharing the most recent information, participating in conferences on HIV, and maintaining contacts with organisations representing PLHIV, particularly with NGOs.

- People who have other chronic diseases receive a lot of attention from the government, whereas an HIV-positive diagnosis causes exclusively negative emotions, which shows that the competence of Lithuanian society in terms of tolerance and empathy is low. In this context, there is a need of PLHIV for moral support from the government through information, media, visits to PLHIV, etc. Furthermore, there is a
need to monitor and control the targeted use of funds allocated by the government to projects, because the products obtained as a result of these projects often lack in quality and effectiveness.

- An HIV-positive person must be competent on HIV prevention issues in order to be able to deal with the existing situation the best they can by himself/herself in protecting the environment from potential unintended infection with/transmission of HIV and to know the ways to protect themselves and manage acute situations caused by the possibility to infect/to get infected with HIV.

- An HIV-positive person must assume moral responsibility for informing one's environment about his or her HIV diagnosis because the awareness of the employer and the environment represents strength and security, whereas non-awareness means insecurity and psychological self-destruction by constantly living under tension.

- HIV-positive people must overcome the psychological barrier inside them and empower themselves to assume responsibility for themselves and the environment at their workplace in terms of prevention. Therefore, NGO initiatives aimed at disseminating information in various work environments not only about HIV / AIDS specifics and prevention but also sharing experiences of PLHIV are of relevance in order to eliminate the entrenched stereotypes about HIV-positive people and view them not as the diagnosis or risk group but as persons, professional and competent employees.

- The existing laws restrict the treatment possibilities for PLHIV in in-patient health care institutions.

- The systematic and continued presentation of experiences of PLHIV enhances the degree of public tolerance and sensitivity and enables to consciously perceive the significance of human dignity in society. This awareness-raising strategy creates preconditions for the integration of PLHIV into society and labour market.

- It is important that NGOs perform the role of initiators of activities and change. For this reason, the meetings of NGO representatives with employers to present HIV-related problems and experiences of PLHIV in various contexts are of relevance. Discussions of NGO representatives and conversations with PLHIV by empowering them to protect their own health and the health of the environment, to assume responsibility for their lifestyle, and to become aware of personal psychological barriers are positive prevention strategies in respect of the social exclusion of PLHIV.
CHAPTER 1: VULNERABILITY ASSESSMENT OF PLWHA IN LITHUANIA
Overview of the HIV/AIDS epidemic in Lithuania

Lithuania, officially the Republic of Lithuania, is a country in Eastern Europe, on the shore of the Baltic Sea, with population of about 3.34 million (2009 data) [1]. It is one of three Baltic countries, and shares borders with Latvia (588 km), Belarus (679 km), Poland (104 km) and Russia (Kaliningrad) (249 km) (Fig. 1) [2].

According to the data of the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV), Lithuania is surrounded by countries that have registered a peak in the spread of HIV over the last few years. Nevertheless, it is a country with low HIV prevalence (HIV prevalence among key populations at higher risk is less than 5 percent) [3]. But during October 2007 – January 2008, the Lithuanian AIDS Centre conducted a study on the prevalence of HIV and other infections among injecting drug users (IDU) for the first time in Lithuania, during which the body the subjects was created by using one of the most effective methods for the creation of a body from difficult to reach and hidden subpopulations, i.e. respondent driven sampling (RDS). The goal of the study was to ascertain the specific features of the HIV related risky behaviour and social networks of IDUs as well as to determine the prevalence of HIV, syphilis, and hepatitis B and C. A questionnaire evaluating risky behaviour (injecting and sexual) was used for the study and IDU blood testing was conducted in order to determine the aforementioned infection signs. 329 men and 71 women participated in the study. The test results revealed that an 8 per cent prevalence (95% CI: 5.5–10.7%) was obtained in testing the respondents’ blood samples for HIV. In light of these results, it is possible to state that Lithuania has a concentrated HIV prevalence [4].

According to data from the Lithuanian AIDS Centre, the first HIV-positive cases in Lithuania were diagnosed in 1988 (Fig. 2). In 1989–1993 the virus spread mainly among men who have sex with men (MSM). From 1994 to 1996 the prevailing mode of transmission was heterosexual transmission, mostly among marine workers who contracted the virus heterosexually. The first person diagnosed as being infected with HIV from injecting drugs was in 1994. HIV infection in this risk group began to spread in 1996-1997 [5].

Since 1988 when the first HIV case was diagnosed in Lithuania, the number of people living with HIV has been increasing (Table 2) [6]. In 2008, 95 new HIV cases and 55 new AIDS cases were diagnosed [7].

During the period of 1988 – 1 August, 2009 a total of 1506 HIV cases and 222 AIDS cases were registered. Out of these, 1260 HIV cases were among men and 246 were among women [8].

HIV prevalence rate in 1996 in Lithuania was 1.45 per 100,000 of the population, 19.87 in 2002;22.78 in 2003; 26.13 in 2004; 29.41 in 2005; 32.11 in 2006; 34.87 in 2007 and 37.08 in 2008 (Fig.3) [9, 10].
Compared to neighbouring countries (fig. 4), the overall HIV prevalence index on 01 January 2009 was 36 cases per 100 000 inhabitants in Lithuania; 173 cases per 100 000 inhabitants in Latvia; and 521 cases per 100 000 inhabitants in Estonia [11].

The AIDS incidence rate has also gradually increased. In 1997 the AIDS incidence rate was 0.08, 0.61 in 2004, and 0.829 in 2007 [9]. In 2008 the AIDS incidence rate was 1.64 per 100,000 inhabitants [10].

Distribution of HIV/AIDS infection in the regions of Lithuania
The highest number of HIV cases during period 1988 – 01 August 2009 were diagnosed in Klaipeda county (450), in second place - Vilnius (286), Kaunas (92), Šiauliai (83), Telšiai (58), Alytus (53), Marijampolė (17), Utėna (27), Panevėžys (19) and Tauragė (11) (LAC data 01 August 2009) [12].

According to the distribution by county at the beginning of 2007, the highest HIV prevalence rate was in Klaipėda at 173.21 per 100,000, followed by Mažeikiai with 59.50, Druskininkai with 40.81, Šiauliai with 30.37 and Vilnius with 27.05 per 100,000 [13].

2008 data shows that HIV infection in Lithuania is generally largest (Fig. 5) in Vilnius county (where the capital is), Klaipėda county (a seaport), and the counties of Šiauliai, Alytus and Telšiai.

**Risk factors for HIV infection in Lithuania**

On the basis of the National HIV/AIDS Prevention and Control Programme 2003–2008, those persons in Lithuania who belong to groups with a high risk of contracting HIV are injecting drug users (IDU) and their family members, men who have sex with men (MSM), sex workers (SW) and their clients, incarcerated and released convicts, incarceration facility employees, police officers, soldiers, young people, adolescents, and health care specialists [14].

According to Lithuanian AIDS Centre data, from the first HIV infection case in 1988 until 01 August 2009, the predominant means of contracting HIV has been injecting drug use. 1096 individuals became infected in this manner during this period. 300 individuals became infected during sex (95 during homosexual sex and 205 during heterosexual sex); 1 case of the prenatal HIV transmission was registered, and the way 109 individuals contracted HIV is unknown [15].

In 2008 (according to 01 January 2009 data), like in earlier years, the same tendencies were noticeable: HIV was contracted was mainly through injecting drug use (44.2 per cent), during sex (36.8 per cent), and in an unknown manner (18.94 per cent) [16].

**The spread of HIV among sex workers (SW).** According to various sources there might be 5000-8000 people involved in the sex industry in Lithuania.

In 2007 not one new case of HIV was registered among sex workers according to laboratory testing. (In 2006 HIV prevalence among sex workers was 1.4 per cent according to laboratory testing.) HIV prevalence among sex workers in Vilnius was less than 5 per cent [9].

A large part of the sex industry is sex workers working on the streets and in ports. The primary problems they face are access to health services, social exclusion, low self-esteem, abuse and social problems [17]. Sex workers (SW) can be classified into three groups by their working profile: street sex workers, call girls and independent high class sex workers. The women and girls are not only from Lithuania, but also from abroad, for example from Russia, Belarus, Ukraine and other countries [5].

**The spread of HIV among men who have sex with men.** Estimates show that the number of people with homosexual orientation in Lithuania is approximately 17,000 – 44,000 (men and women) [18, 19]. The first HIV case in MSMs was reported in Lithuania in 1989. Up to 1997, HIV in Lithuania was reported as being transmitted through sexual contact, mostly among MSM and among seafarers who contracted the virus heterosexually in countries with epidemics [20].

The HIV prevalence index among men who have sex with men was 1.2 per cent in 2007 according to laboratory testing (0.7 per cent in 2006). HIV prevalence among men who have sex with men in Vilnius was less than 5 per cent according to laboratory testing [9].
The spread of HIV among injecting drug users. Injecting drug users make up a significant risk population because of their risk behaviour and much higher HIV prevalence in neighbouring countries [20]. The first HIV positive injecting drug user was reported in 1994. In 1996, already half of diagnosed HIV cases were due to injecting drug use. In 1997 about 90% of all HIV cases were attributed to this mode of transmission [19].

According to 2007 test data from the implementation of the UNODC project ‘HIV/AIDS Prevention and Care among Injecting Drug Users and in Prison Settings in Estonia, Latvia, and Lithuania’, Lithuania had 4300 problematic drug users in 2006, 3200 of which were injecting drug users [21].

According to State Mental Health Centre data, the number of individuals with dependencies at the end of 2008 consisted of 69 340 individuals, of which 91.6 per cent had a dependency on alcohol and 8.4 per cent on drugs [22].

In analysing the 2008 sex distribution of individuals with a drug dependency, it was noticed that 81.1 per cent were men and 18.9 per cent women. At the end of the 2008, 5809 individuals had a drug dependency [22].

The prevalence of drug addiction in 2008 was 172.9 cases per 100 000 inhabitants [4]. According to AIDS Centre test data, HIV prevalence among injecting drug users was 8 per cent during 2007–2008 [4].

Officially registered injecting drug users in Lithuania have shown a steady increase over recent years – 3521 people in 2000 compared to 5011 people in 2004. The estimated number of IDUs was 7,000 to 11,000 in 2005. Studies among IDUs attending drug treatment centres, needle exchange programmes, hospitals or other clinics found an HIV prevalence ranging from 1 to 3% in the period between 2000 and 2006 [18]. HIV prevalence was 8 per cent among injecting drug users according to data from a study conducted by the Lithuanian AIDS Centre in 2008. [4].

The quality of data on PLHIV in Lithuania

The objectives of the National HIV/AIDS Prevention and Control Programme 2003–2008 foresee ensuring that responsible institutions collect, accumulate, analyse, and supply statistical data about sexually transmitted infections, HIV/AIDS, and tuberculosis and, on the basis of WHO recommendations, use a second generation HIV monitoring system [21].

Narcological patient (registration) accounting is conducted and data about the prevalence of mental disorders among inhabitants were collected and analysed by the State Mental Health Centre. The State Mental Health Centre is the institution responsible for implementing the description, approved in 2007, of the procedure for monitoring individuals, who have contacted a personal health care establishment due to mental and behavioural disorders while using narcotic and psychotropic substances. The dynamics of the incidence, second contact, and prevalence indices are analysed in implementing this order as well as in accordance with the investigation of infectious diseases and provided mental health services [21].

The National HIV/AIDS Prevention and Control Programme 2003–2008 accents the need to improve health care, protection, and care for persons living with HIV and AIDS. In pursuing the goal it is imperative to develop the voluntary consultation and testing services and to ensure their confidentiality and anonymity [14]. The order concerning the epidemiological care of sexually transmitted infections, HIV, and AIDS in personal and public health care establishments also foresees that personal health care establishments organise the taking of blood samples from members of risk groups (injecting drug users, sex workers, men who have sex with men, etc.) and its shipment to a suitably licensed laboratory for HIV testing [23].

Lithuanian health specialists collect data on HIV incidence and prevalence in Lithuania, compile biological markers of HIV, hepatitis B, and hepatitis C from drug users, patients with sexually transmitted infections, partners of PLHIV, blood and
organ donors, all pregnant women, people in military training, anonymously tested people, prisoners, health care personnel and people tested for prophylactic purposes [9].

The Lithuanian AIDS Centre (LAC) is the main prevention, clinical and referral diagnostic centre for HIV. HIV testing is voluntary, except for the mandatory testing of donor blood, organs and tissues. Epidemiological data were obtained from the Lithuanian AIDS Centre database, which contains coded and protected epidemiological, diagnostic, and clinical information on all identified HIV cases in Lithuania.

Lithuania has had a national Monitoring and Evaluation (M&E) Action Plan since 2003 which was developed in consultation with civic society, including people living with HIV. The National HIV/AIDS Monitoring and Evaluation (M&E) Action Plan was revised with the assistance of international experts in 2005. A functional M&E Unit is based in the Lithuanian AIDS Centre. The M&E Unit manages a central national HIV and STI database [5]. The country reports on HIV, including HIV surveillance data and STI data every year at www.aids.lt. The Lithuanian AIDS Centre reports every year on HIV and drug use through annual reports prepared by the Drug Control Department under the Government of the Republic of Lithuania [9].

In 2006, the Lithuanian AIDS Centre launched the implementation of a UNDP project entitled “Mid-term Review of the National HIV/AIDS Prevention and Control Program 2003-2008 and Introducing CRIS (Country Response Information System) Nationwide” [9]. Within the framework of the programme, 240 decision makers, inter-sectoral stakeholders and specialists working with populations at higher risk were trained [18].

Lithuanian practice in the area of HIV prevention and control is acknowledged in the EU, and Lithuanian experts are often invited to share their best practices in the areas of a multi-sectored response to HIV, and preventive and health promoting education, using active and informal methods and working with populations at higher risk [18].

**Portrait of PLHIV and other people attitude towards PLWHIV in Lithuania**

**Portrait of PLHIV in Lithuania.** According to data on social characteristics from 2004, the majority of HIV-infected persons have had a long experience of injecting drug use, with an average of 5 years, but there were those who have been using injecting drugs for 10-20 years [19].

According to 2008 data from the Drug Control Department under the Government of the Republic of Lithuania, the youngest person diagnosed with HIV was 15, the oldest 68. The ratio of men and women who contracted HIV declined. Among those diagnosed in 2002 it was 12:1, in 2003 7:1, in 2004 5:1, in 2005 3:1, in 2006 3.5:1, and in 2007 2.3:1. [4].

The average age of individuals newly diagnosed with HIV in 2008 was 35. The average male age at the time of diagnosis was 36 in 2008 (35 in 2007). The average female age at the time of diagnosis was 32 in 2008 (30 in 2007) [24]. In analysing the HIV incidence data for 2008, it was determined that 53.7 per cent of the individuals did not have social insurance at the time of diagnosis, 37.9 per cent had social insurance, and the insurance status of 8.4 per cent was not indicated [24].

According to the available data, 26.3 per cent of new HIV cases were unemployed, 26.3 per cent black collar workers, and 11.6 per cent white collar workers. In analysing the data about the use of protective measures, it was revealed that the majority of persons who contracted HIV rarely (45.3 per cent) or never (17.9 per cent) used condoms. Only 7.4 per cent of new HIV cases always used protective measures during sex. 29.5 per cent of the files do not record usage [24].
It was determined in 2008 that according to education, 53.7% of HIV-positive persons had a secondary education, 22.1% had basic education, 8.4% had higher education and 2.1% had primary education. There was no information in 13.7% of the education protocols.

**Attitude towards PLWHIV in Lithuania.**

In 2003 a public opinion poll about vulnerable groups showed that during the last 13 years tolerance of those with HIV has greatly increased. In 1990, 77.6% of interviewees admitted not wanting to live near persons with HIV, in 1999 55 per cent, and in 2003 only 49 per cent. But the last public opinion research again showed a drop in tolerance as the number grew to 70 per cent. The greater need to maintain a distance was caused by ex-convicts and drug users: In 2003 57.4 per cent and 81 per cent respectively of Lithuanian inhabitants did not want to live near such individuals, in 2005 77 per cent and 96 per cent respectively. Young people (15–29 years old) are more tolerant of people with HIV/AIDS than people 50–74 years old. Those with a university education and higher income are usually more tolerant of people with HIV [25, 26].

In 2005, a Social Tolerance Study was conducted by the Coalition “Galiu gyventi” together with the National Health Board. The survey was aimed at measuring tolerance levels of staff in local governments, health care, educational and social sectors towards 4 vulnerable populations (drug users, former inmates, sex workers and people living with HIV). Analysis of the data collected showed, that the respondents were most tolerant towards individuals released from places of detention, relatively less towards people living with HIV and engaged in providing sex services, and the least tolerant towards drug users. Analysis revealed that the highest level of intolerance towards the above-mentioned vulnerable populations was from professionals of the health care sector, pharmaceutical, nursing and obstetrics sectors [26].

The tolerance of others towards the most vulnerable social groups that are likely to be exposed to social exclusion can have an impact on the preparation of programmes, their implementation, and political support of HIV and programmes for the prevention of drug use and other programmes. It also indicates achievements in the field of education [26].

**Lithuanian Policy Response to HIV in Lithuania**

Lithuanian policy in the area of drug use and HIV/AIDS prevention and control is defined in strategies and programmes. The country’s most important strategic document in the area of HIV/AIDS prevention and control is the National HIV/AIDS Prevention and Control Programme. The first National HIV/AIDS programme was created in 1989 and implemented during 1990–1992. Six programmes at this level have so far been approved. In 1996 the HIV/AIDS Prevention and Control Programme was included in the list of priority national health programmes. The Lithuanian health programme, which was adopted by the Seimas in 1998, foresees maintaining a low HIV/AIDS incidence rate in the country until 2010 [28].

The main strategic document implementing the health strategy, which names the main goals of the country’s response to HIV is the National HIV/AIDS Prevention and Control Programme 2003–2008 [14]. The programme was created on the basis of the principles of the global AIDS strategy, the recommendations in the World Health Organisation’s policy document ‘Health for All in the 21st Century’ and the United Nations HIV/AIDS Programme (UNAIDS), the ‘Declaration of Commitment on HIV/AIDS’ of the United Nations General Assembly, and the resolutions of the Republic of Lithuania that seek to implement the obligations to the European Parliament and the European Council. The programme priorities were set while taking into consideration the rapidly changing epidemiological situation in Lithuania and the neighbouring countries. The HIV transmission routes and tendencies, the growing experience of the health and other sector specialists, and modern scientific achievements were taken into consideration [28].

By resolution no. IX-2110 of 8 April 2004 ‘on the Approval of the National Drug Control and Drug Addiction Prevention Programme 2004–2008’, the Seimas of the Republic of Lithuania approved the National Drug Control and Drug Addiction Prevention Programme 2004–2008 [29]. The work plans for implementing the measures established in the Programme are annually drawn up and approved. The goal of stopping and reducing the incidence of drug addiction, determining and implementing the main state policy guidelines and activity directions in the area of drug addiction prevention and drug control, and increasing the effectiveness of the drug addiction prevention in Lithuania have been raised as strategic objectives in the programme. The programme stresses that it is imperative to ensure the implementation of the prevention of the incidence of drug addiction related infectious diseases, the use of low-threshold measures, and the development of medical and social rehabilitation for those persons dependent on psychoactive substances who want to recover [29].


The 4-year project ‘HIV/AIDS Prevention and Care among Injecting Drug Users and in Prison Settings in Estonia, Latvia, and Lithuania’ of the United Nations Office on Drugs and Crime began operating in 2006. The main goal of this project is to create a favourable environment in all of the countries participating in the project so that the HIV/AIDS prevention and care activities can be conducted more effectively among injecting drug users and convicts, while focusing on normative policy, strengthening capabilities, and the programme aspects of the national HIV/AIDS prevention activities. Four work groups, one of which is HIV Prevention in Prisons, were created for the implementation of the project [21].

**Legislation addressing the fight against HIV in Lithuania**

There are a number of laws and legal acts adopted in Lithuania that regulate all possible aspects of the health care system. Most of them are of general nature, applicable to all health care users. Besides these there are also special regulations that indicate priority for medical aid and health care for specific groups of patients. Drug users and persons living with HIV are one of these target groups that are indicated in most legal acts and require special attention not only for the treatment and rehabilitation purposes of patients themselves, but also for the maintaining and promoting of public health in general.

**Health care**

Article 47, paragraph 2, subparagraph 7 of the Law on the Health System of the Republic of Lithuania of 19 July 1994, no. I-552 (Valstybės Žinios (Official Gazette), 1994, no. 63-1231; 1998, no. 112-3099) foresees state guaranteed (free) health care, assigning to it the health care of persons with tuberculosis, sexually transmitted infections, HIV (AIDS), infectious, endocrinial, mental, oncologic diseases, alcohol dependency syndrome, drug addiction, toxicomany, other diseases on the list established by the Ministry of Health, and pregnant women [30].
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

The Minister of Health has issued the Order on the approval of the methods for the diagnostic and outpatient treatment of diseases caused by arthrosis, HIV, chlamydia trachomatis that are compensated from the resources of the Compulsory health insurance fund budget [29].

An Order on approval of prescription of post exposure HIV prophylactics indicates that post exposure HIV prophylactics is preventive treatment when blood, liquids with blood or other organism substances of the person infected or suspected of being infected get on the affected skin, mucous membrane or into the organism of another person [32]. The medicaments for post-exposure HIV prophylactics are compensated from the Compulsory Health Insurance Fund budget, if the exposure occurred during working, performing professional duties and/or for persons having suffered at the hands of violence or being assaulted, when in such cases that are registered there is a procedure established by law. In other cases persons have to pay for the medication themselves [30].

The National HIV/AIDS Prevention and Control Programme 2003–2008 [14] indicates that harm reduction measures are those measures, by which it is sought to reduce the negative economic, social, and health consequences connected with drug use. Such measures consist of syringe and needle exchanges, pharmacotherapeutic opioid preparations, condom distribution, etc. Special attention is foreseen in the programme's priorities for groups at risk of contracting HIV (drug users, sex workers, convicts, etc.). In implementing the programme's measures collaboration is foreseen with various organisations, including non-governmental organisations (NGOs), working in the area of drug addiction and HIV prevention. It foresees expanding the low-threshold health care office network, intensively informing young people, and improving the health care, care, and treatment of persons living with HIV/AIDS. It foresees strengthened HIV/AIDS epidemiological care and laboratory diagnostics.

The Minister of Health order ‘On the Approval of the Description of the Procedure for Implementing Programmes for Reducing the Harm of Narcotic and Psychotropic Substances’, which foresees free health care and social assistance for injecting drug users and their partners, was approved in 2006. Low-threshold offices for narcotic and psychotropic substance users must supply the following services: a needle and syringe exchange, disinfectant and condom distribution, and health education in an effort to reduce risky behaviour, inform, and advise [33].

Education and science.

The original youth HIV/AIDS education programmes were initiated and prepared by the specialists at the Lithuanian AIDS Centre in 1992 and became the basis for the Ministry of Education and Science to include HIV (AIDS) related questions in education programmes. As a consequence the schools now provide pupils with knowledge about HIV (AIDS) and shape their attitudes and values. Since 1993 teachers have actively organised HIV/AIDS prevention and related questions among pupils since their knowledge about HIV/AIDS and other STIs greatly depends on the sophistication, experience, and readiness of teachers to teach on these topics and in general on the specific school policy and strategy in this area [9].

At this time youth education on HIV (AIDS) and related questions is considered a priority. The ‘Programme for Preparation for Family life and Sex Education’ was approved (Valstybės Žinios (Official Gazette), 2007, no. 19-740) [32], implemented in accordance with the methodological teaching aids prepared by a team of authors ‘Organisation of Programmes for the Preparation of Children and Adolescents for Family Life’, and the ‘Programme for Preventing the Use of Alcohol, Tobacco, and Other Mind Altering Substances’ [35], which encompasses preschool, primary, general, and secondary education, was implemented.

Prevention work groups, the functions of which are defined by the Law on the Minimum and Medium Care of Children, were created in the schools [36]. Social teacher staffs have been introduced and the competency of the public health care specialists has been increased [37]. HIV/AIDS topics have been integrated
into biology and ethics lessons, health education consultants have been prepared (primary, general, and secondary education), their activities being regulated by the Regulations for the Preparation, Activities, and Accountability of Education Consultants [38]. The improvement of teacher qualifications is being conducted at the Teacher Professional Development Centre, and the education development centre is responsible for the education content.

The specialists at the Lithuanian AIDS Centre actively help teachers in HIV (AIDS, STI) and drug addiction prevention work. They give teachers the latest knowledge about the HIV (AIDS) epidemiological situation and ways and means of preventing it. They encourage teachers to actively participate in prevention work and actively use education aids [9].

After evaluating the life skills formation content connected with education on HIV (AIDS) questions in schools (HIV (AIDS) questions are examined in biology and moral education and informal education programmes.), it is possible to draw the conclusion that HIV education based on life skills formation is being conducted and that school leaders have undertaken to solve prevention problems in schools: organise the prevention of narcotic and psychotropic substance use and of HIV (AIDS), prepare annual activity plans, report the use of alcohol, tobacco, and other mind altering substances, HIV (AIDS) prevention, and child occupation, and also submit suggestions for improving the situation [9].

An analysis, conducted at higher education schools (KMU, U, and VPU) in 2006, of the role of higher education institutions in preparing health care specialists, teachers, special teachers, and physicians for work with the most vulnerable social groups (drug users, people living with HIV and AIDS, sex workers, immigrants, convicts, ex-convicts, and young people) showed that the HIV, AIDS, and related problems discussed in lessons are mostly connected with young people and drug users. The results showed that Lithuania's higher education system does not devote sufficient attention to HIV, AIDS, and related problems because the programme and course topics are limited. The universities also have an insufficient material base – literature on this topic [27].

Employment and access to social services. According to the Labour Code of the Republic of Lithuania, no discrimination based on language, race, sex, political opinion, philosophical belief, religion and sex or similar reasons is permissible in a work relationship [37]. HIV patients receive state support as other patients do - for example, state support for buying a dwelling or renting. In general there are, no regulations limiting the right of people infected with HIV to work, however it can be said that in some cases there is still a requirement for compulsory HIV testing [40].

Government and lesser acts foresee a mandatory check for HIV in pursuing an education and in working: everyone wanting to work and already working at sea must be tested once a year. (HIV and AIDS are a contraindication for all categories of marine workers.) [41, 42]

Restrictions on the right of HIV-positive persons to adopt a child or become a guardian or foster parent are likewise foreseen; the person must have HIV-negative status, i.e. a person with HIV cannot adopt or become a child’s guardian or foster parent [43].

In sending minors to special children’s homes, AIDS test data must be submitted together with the other medical documents [44].

Lithuania has implemented a human trafficking prevention and control programme [45]. The Ministry of Foreign Affairs has created a list of NGOs and foreign organisations, which provide assistance to sex workers and human trafficking victims. Woman brought to Lithuania can obtain assistance at the Missing Persons’ Families Support Centre, Caritas Lithuania, Klaipėda Social and Psychological Support Centre, Woman’s crisis centre, Lithuanian AIDS Centre, and other organisations.
In-patient assistance is provided by five specialised dependency centres and nine psychiatric hospitals. Methadone replacement therapy programmes are used in Vilnius, Kaunas, Klaipėda, Panevėžys, and Druskininkai. Injecting drug users can also go to low-threshold service offices in Alytus, Druskininkai, Kaunas, Klaipėda, Mažeikiai, Šiauliai, and Vilnius [21].

There are 4 NGO bringing together and aiming at empowering PLHIV in Lithuania. The non-governmental sector has participated in programme development and the decision-making process.

**Summary of the Desk Review**

In Lithuania the most vulnerable groups are injecting drug users, men who have sex with men, and sex workers. Young people, adolescents, convicts, etc. are also assigned to high-risk groups.

Lithuanian law provides a sufficient number of laws which regulate narcotic drugs and psychotropic substance users for persons using services and testing for HIV infection. Lithuania Republic of Law on the health system for persons dependent on drug usage guaranteed free health care, but the Lithuania Republic Law on health insurance among persons who are-covered by state funds, suffering from drug addiction are not mentioned. De jure, people living with HIV have equal rights for work and education if they possess the required abilities or skills. But de facto the situation differs, mainly, because of low community tolerance and stigma towards them.

HIV incidence is determined by social and psychological factors, therefore in many countries of Europe and the world no less attention is devoted to these factors than to health care. Persons living with HIV need integrated health, psychological, and social assistance corresponding to their needs and socioeconomic situation. The co-operation of various specialists and officials is an essential precondition to improving patient-oriented services. The family members and sexual partners of persons living with HIV must be assured free HIV testing, consultation, and psychosocial assistance. Only social assistance of a consultative nature is provided in Lithuania to people living with HIV/AIDS, but no occupation, training, or other integration services are provided nor are any care and treatment questions of people living with HIV/AIDS being resolved because there are no prepared methods or created conditions, the provision of psychological assistance is insufficiently ensured, and insufficient attention is devoted to prevention work. In solving these problems, it is essential to involve patients and non-governmental organisations, who can actively participate in HIV/AIDS prevention activities by providing consultation services and solving other problems important for HIV/AIDS patients. These organisations could contribute by reducing the stigmatisation and discrimination connected with HIV [46, 47].

The most important strategic document, which currently exists in Lithuania and is devoted to solving the problems of people living with HIV/AIDS, is the National HIV/AIDS Prevention and Control Programme 2003–2008 [14]. A draft of the new National HIV/AIDS Prevention and Control Programme 2009–2012 was recently created, which is being co-ordinated among the main partners after commentary was received from the World Bank’s AIDS Strategy and Action Plan (ASAP) service and will be submitted in the first quarter of 2009 to the Lithuanian Government for approval.
CHAPTER 2: RESEARCH METHODOLOGY
The most frequent characteristics of social attitudes regarding HIV / AIDS and PLHIV are comprised of the following aspects [48]:

- **defiance** – the defiant attitude of the public at large toward the need for knowledge on HIV / AIDS;
- **disassociation** – the transfer of responsibility for the spread, prevention and prophylaxis of HIV to “others” who are represented by the health, educational and social services sector;
- **risk practice** – the problem of risk groups, i.e. relevance of HIV / AIDS only for representatives of risk groups;
- **fear of infection** – the individual’s irrational behaviour and uncontrolled emotional reactions when communicating with PLHIV;
- **distrust and insecurity** – the perception of mutual stereotypes of the public and PLHIV by ignoring them and blaming each other;
- **moral transcendence** – moral norms violated by a person living with HIV, for which this person was “punished” when he or she was diagnosed with HIV;
- **superficial dissemination of information provided by the media** an avoidance to present the positive experience of PLHIV and also examples of discrimination, which would create preconditions for discussions that would increase the level of tolerance in society;
- **secrecy** – the consideration of PLHIV problems in society as “invisible” and thus not discussing them openly, as if they were overcome by a shadow by shame;
- **uncertainty** – the limitations on access to health care services to PLHIV;
- **impact of the environment** – the need to perceive that the problems of PLHIV are not only the problems of this group, but of the whole society, which is comprised of psychological, social, medical, educational, managerial and labour market attitudes.

A qualitative research strategy was chosen to analyse the complex and multi-faceted problem of the social vulnerability of PLHIV [49]:

1. Qualitative research is concentrated on the relationships between variables that represent the life and work contexts and situations of PLHIV that are not easily measurable. The understanding revealed by the results of the qualitative research creates the preconditions to inform specific institutions that have the power to make decisions regarding the existing obstacles, problems and needs in the decision-making process aimed at improving the situation of PLHIV.

2. Qualitative research enables representatives of different groups who are connected to HIV issues to participate in the survey process and creates preconditions to collect an abundance of information, which is unique.

3. Qualitative research is appropriate for the in-depth exploration of unique phenomena, the information of which is obtained from small target samples that have experience with HIV-related issues.

The **research objective** is to reveal the factors determining the social exclusion of PLHIV in personal environments, educational system, health care system, labour market and in interactions with non-governmental organisations.

**Research tasks:**

1. To determine and summarize the experiences of PLHIV in the personal environment, educational system, health care system, labour market and in interactions with non-governmental organisations.
2. To reveal the attitudes and perceptions of the representatives of the educational services sector, health care sector, non-governmental sector and the labour market regarding the situation of PLHIV.

3. To prepare and submit recommendations in different policy fields so as to enable the elimination of discrimination, and the promotion of the social integration of people living with HIV (AIDS), particularly in the health care, education and employment sectors.

Research design

The constructed research design is based on the integrity of the following two knowledge positions:

- **The position of socially constructed knowledge** allows for the forming of knowledge based on alternative processes and the collection of preconditions. In this respect, it is sought to understand the world of the study’s participants that they live and work in. By providing information, the study participants develop subjective meanings of their experiences oriented towards specific objects. These meanings are different and varied, creating preconditions for the study investigator to see the complexity of the attitudes of study participants rather than narrow the meanings to a few ideas or categories. Therefore reference is made to the respondent's attitudes toward the situation being examined. The questions are wide-ranging and generalizing; in this way conditions are created for the study participants to construct meanings concerning the situation or a meaning arising out of the interaction between the study investigator and the respondent. The more open questions are, the better it is, because the study investigator has the possibility of listening carefully to what the respondent says and understand what the study participants do in their life and work environments. In this respect, emphasis is placed on the process of interaction between individuals, while through the qualitative data that was obtained; meaning is attributed to the experiences of the study participants [50, 51].

- **The position of sustainable or participant knowledge** is concentrated on “marginal” groups. With the study results that were obtained, a voice is given to these people, which becomes a unifying aspect when implementing target changes. This knowledge position is a point of reference for groups and persons who experience exclusion or are deprived of their rights [52, 53].

The qualitative research design should be implemented based on the international qualitative research methodology “Guideline for a Qualitative Research Methodology to Assess the Social Impacts of HIV and Identify Priorities for Advocacy Action Assessment” [49], which is comprised of the following two stages:

**Stage 1** – individual in-depth interviews, of which at least twenty PLHIV are interviewed;

**Stage 2** – target group interviews. Where three target groups representing the education sector, the health care sector, the non-governmental sector and the business (labour market) sectors are interviewed.

The qualitative study data collected during both stages should be analysed separately by applying a qualitative content analysis method (please refer to a more detailed description of the methods in Section “Method”).

Research ethics

The study was based on the following provisions [54]:

- People were involved in the study after they had become familiar with the research content, and their verbal and written consent had been obtained (by signing the document on research ethics);

- participation of the respondents in the study was voluntary;
information about the objectives of the study was accurate;

- the respondents were not misled concerning the research objectives, research process, and form and possibilities of presenting the results;

- the research participants were not forced to perform any actions humiliating their dignity;

- during the study, compliance with the laws and conventions protecting human rights was observed;

- the participants were not subject to any physical pain or stress during individual or focus group interviews;

- the privacy of the participants was not violated;

- the anonymity of the participants was not violated;

- the participants were treated in a respectful and fair manner.

The study was carried out in compliance with the following main principles of research ethics [54, 55]:

**The right to non-violation.** The investigators were guaranteed that the survey would have no negative impact on their physical, mental and social health; the survey was planned and carried out by a highly-qualified scientist having extensive knowledge of general scientific research methodology and competence in qualitative research methodology and the application of specific methods; qualitative data were collected by persons possessing an adequate level of education who were given briefings on the subject; during the data collection process, the interviewers and the target group leaders were ready to terminate the survey at any time if there were any suspicion that the participation of the respondents had any impact on the deterioration of their health; the investigators, when collecting information, and the scientist, when analysing qualitative data, thoroughly reflected on and selected the definitions, terms and phrases which they used when asking questions of the survey participants and summarising the obtained survey results during the analysis in order to protect the participants from psychological vulnerability.

**The right to non-exploitation.** The interview participants did not experience any dissatisfaction as a result of their participation, i.e. they did not experience any psychological pressure, fear, anxiety, etc.; in all the stages the, investigators ensured that the participation of the respondents and information provided to them would not be used against the research participants; during individual and focus group interviews the participants were placed in a specific environment where they had to communicate face-to-face with the investigators who were collecting information; therefore, the investigators collecting information guaranteed that the investigator-participant relationships in any form would not be used with bad intentions.

**Utility of research.** The survey participants consciously agreed to participate in interviews and focus groups because it is important for their current life situation – research-based arguments provide scientific evidence and proposals for changes; the participants perceived that their participation in a concrete survey has a positive impact on the evolution of society and development of knowledge, however, the benefit of this particular research in respect of the situation of PLHIV in Lithuania was explained to each survey participant.

**Respect for personal dignity.** The study participants were treated as independent individuals capable of controlling their personal behaviour; each study participant had the right to make personal decisions regarding their participation / non-participation in the survey or withdrawal from the survey (individual or focus group interviews) at any stage.
Justice. The selection of participants was based on scientific criteria; the factors of benefit, trustfulness or compromise were not relied on so that the “right” persons would participate in the research; the participants had the possibility to ask questions from the investigators collecting the data about the survey and obtain detailed information; the participants were treated in a respectful and courteous manner throughout the entire survey.

Privacy. During the survey, the participants were guaranteed that they would be protected to the maximum extent from tiresome questions about their personal life and that demographic questions would be related only to the needs of the survey; however, in case the participants did not want to answer them, their decision would be respected at all times; the participants had the right to expect that their anonymity and confidentiality will be protected concerning the information provided in the survey; while observing the principle of anonymity, the investigators collecting data and the scientist analysing the data could not link the information provided by the participant with his/her personality.

Confidentiality. The research participants were verbally guaranteed that information presented for the survey – the “raw” qualitative data collected during individual and focus group interviews and transcribed in sound and text electronic files - would not be distributed; unprocessed information would not be accessible to any person who is not related to the project, and more specifically to the research part of the project; the participants would not be identified from the description of the survey (all first names and surnames, names of institutions and organisations, cities, etc; each computer file with information provided by each research participant was given a code, for example, X, Y, Z); a code was assigned to each computer file containing information provided by the participant; access to computer files was granted only to the research coordinator and the scientist analysing the qualitative data.

Anonymity. The research participants were guaranteed that precise data provided by them would not be published or distributed; each survey participant signed a form on compliance with the principles of research ethics before every individual and focus group interview.

Research sample

The first stage of the qualitative research – the characteristics of the research participants for individual in-depth interviews

Twenty research participants were selected for individual interviews using the method of targeted maximal diversity selection, where sample units are chosen purposefully so that the research sample is comprised of as many diverse cases of the object under investigated as possible. The survey was directed at identifying common features characteristic of all the cases being investigated [56 p. 33].

A total of four women and sixteen men participated in the research. In the whole interview sample, the age of the survey participants varied between 24 and 49 years of age (the average being 35.65 years of age). According to gender, their age range is as follows:

- the age of women varies between 24 and 40 years old (the average being 32 years old);
- the age of men varies between 25 and 49 years old (the average being 36.56 years old).

Distribution of the survey participants by ethnic group is as follows:

- two women representing the Russian ethnic group and two women representing the Lithuanian ethnic group;
- eleven men representing the Lithuanian ethnic group, four men representing the Russian ethnic group, and one representing the Polish ethnic group.
The period of living with HIV between survey participants varies between 2 days and 18.5 years (the average is 4.83 years).

Eleven out of twenty survey participants do not have children, whereas nine of them have children. Among those who have children, four of them have two children, one has three children, and four of them have one child. All four women who participated in the interview have children. The survey participants who have children stated that their children are not infected with HIV. Five men claim that their children had been born before they got infected with HIV, while one woman...
states the fact, i.e. that her child had been born before she got infected with HIV. One child was born after the mother had been infected with HIV, whereas in the other case (i.e. the woman who has three children) – the first child had been born before the woman got infected with HIV, whereas the other two children were born after she had been diagnosed with HIV. One survey participant indicates that she had not been tested for HIV neither before the childbirth nor during it, and that she had been diagnosed with this disease only after her child had been born.

The majority of the survey participants have not finished secondary school, for example having completed the ninth or tenth form. Only one of the participants is currently studying at a vocational school. Two research participants intend to start studies in the autumn of 2009 in order to fully complete their secondary school education (the eleventh and twelfth forms). Three survey participants have realistic plans to study in 2009-2010 – one person will attend a course for acquiring professional qualifications organised by the Labour Exchange in the autumn of 2009, one person plans to study at a college, and the third intends to study at a vocational school. The other fourteen interviewees do not have any plans to study or learn either at the present time or in the future.

As we can see, some survey participants are studying or planning to study in order to acquire professional qualifications. Some of them do not plan to learn or study, claiming that they do not have time. Some lack financial resources because they need to take care of their children. Sometimes the efforts of HIV-positive persons to study and acquire a profession are fruitless: the possibilities of finding a job with a certificate obtained in the Labour Exchange are minor. This means that the educational system is not prepared to create possibilities for PLHIV to integrate through acquired professional qualifications. This situation strongly demotivates HIV-positive people, and they live under constant stress. The interviewed persons who work and whose health is good do not have any plans to study or change something in their lives. There are some thoughts about possible studying in the future, but if their health is bad, studies will remain in the background. One of the survey participants voiced his desire to study social work because “this would help

<table>
<thead>
<tr>
<th>Code of survey participants</th>
<th>Employed / Unemployed</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) A</td>
<td>Unemployed (no income; supported by mother)</td>
</tr>
<tr>
<td>(2) B</td>
<td>Unemployed (no income; supported by friends)</td>
</tr>
<tr>
<td>(3) C</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(4) D</td>
<td>Employed (services sector)</td>
</tr>
<tr>
<td>(5) E</td>
<td>Unemployed (receives social assistance)</td>
</tr>
<tr>
<td>(6) F</td>
<td>Unemployed (receives social assistance)</td>
</tr>
<tr>
<td>(7) G</td>
<td>Employed (cultural sector)</td>
</tr>
<tr>
<td>(8) H</td>
<td>Employed (unspecific sector)</td>
</tr>
<tr>
<td>(9) J</td>
<td>Unemployed (no income; supported by mother)</td>
</tr>
<tr>
<td>(10) K</td>
<td>Unemployed (disability pension)</td>
</tr>
<tr>
<td>(11) L</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(12) M</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(13) N</td>
<td>Unemployed (raises a child, social benefit for the child)</td>
</tr>
<tr>
<td>(14) O</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(15) P</td>
<td>Employed (private sector)</td>
</tr>
<tr>
<td>(16) R</td>
<td>Employed but on sick leave (hospital treatment)</td>
</tr>
<tr>
<td>(17) S</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(18) T</td>
<td>Unemployed (informal work)</td>
</tr>
<tr>
<td>(19) U</td>
<td>Unemployed (unemployment benefit)</td>
</tr>
<tr>
<td>(20) V</td>
<td>Employed (social sector)</td>
</tr>
</tbody>
</table>

Table 2
Occupational Status of the Survey Participants
in his work: "would provide new knowledge, and I would learn how to apply my practice in life better" [(26) Participant C].

The participants living in small towns find it difficult to survive not only morally and psychologically, but also financially due to their status as a drug user (drug addict). Usually there is no methadone programme in their town, and the participants consider this situation as complicating their life because the majority of them are inclined to participate in the methadone programme. The research participants are well acquainted with the social care system and are aware of available social benefits. Many of them are registered at the Labour Exchange and thus receive a minimum social benefit. There are some interview participants who want to acquire professional qualifications, but their main argument is the desire to continue the job search according to the professional qualifications they have, and the benefit paid during the learning period, which would be allocated between dwelling, food and, most important, acquisition of drugs, is very necessary. Several interview participants state that the self-care of a person living with HIV is very expensive due to various complications – regular physical activity/sport, use of vitamins and food supplements, the regular use of medicines due to negative health changes (complications), etc. are needed. Priorities must be determined; thus learning does not come first.

Five out of twenty survey participants have a job and work, and one female participant has a job but currently is on sick leave and is undergoing in-patient hospital treatment. One person indicated that formally he is unemployed, but that he carries out auxiliary works in the private sector.

Six survey participants receive social unemployment benefits; one participant receives a social benefit for the child; one interview participant receives a disability pension; two participants receive social assistance; two persons are financially supported by their mothers and one is supported by friends.

Only three survey participants indicated that they have no source of income. The other seventeen persons indicated average financial resources which they allocate for dwelling, food, clothing and medicine each month. The received monthly income varies between 256 litas and 2,400 litas per month (the average of monthly income of all the study sample is 705.41 litas).

The income received by the survey participant varies. Some HIV-positive individuals do not have any income for living. They often receive help from friends concerning dwelling, food, etc. Their income is not large; therefore, HIV-positive persons find it difficult to survive without the help of others. One of the main sources of income is family members or friends. The study participants reflect that their financial situation was better before the diagnosis, and now their income has decreased and they have to limit themselves. Some research participants are not satisfied with the unemployment benefits they receive; therefore, they work in the private sector and carry out auxiliary works. This proves that they are capable of enabling themselves for self-care through work. Some participants do not have a formal job and are engaged in informal activities (called “unofficial” by society).

Three out of twenty individuals who participated in the interview are not dependent on drugs and have never used them; one study participant has fully completed a rehabilitation course and has not used any drugs for several years. The other sixteen survey participants stated that they are dependent on drugs: three study participants currently do not use drugs, whereas thirteen interviewees do.

The majority of the survey participant admits that their infection with HIV is linked with the use of drugs. Many of them have used drugs and consider themselves to be dependent on drugs. A small percentage of the interview participants claim that they have never used drugs.

A major part of the male participants indicate that they have never had sexual intercourse in exchange for money or with men because their relationships were heterosexual (twelve survey participants). A small number of the make interview participants claim that they have had relationships only with men or their sexual relationships were homosexual (three participants). One survey participants stated that he has had sexual intercourse with both women and men, i.e. he had bisexual relations. Female participants (four) claim that they are
heterosexual. One female participant states that she has provided paid sexual services to men. Three research participants have their own house – one has a private dwelling-house and one has obtained a mortgage loan from the bank for the acquisition of his own apartment. Some participants live with their relatives: two persons live with cousins, one lives with his grandmother, and one female participant lives with her life partner’s parents. Five survey participants live with parents: three persons live with their mother and two share dwelling with their parents. Two participants received help from their friends regarding a place to live – friends took them in and the interview participants pay them a symbolic rent for the dwelling. Four persons rent apartments, and two live in the rehabilitation centre. The research participants living in the rehabilitation centre feel safe and dignified there. Although they have a place to live, some individuals are planning to change their lives: to change their place of residence, to change the dwelling in order to distance themselves from their “former” life so that there is no relapse. Thus, only a few participants have their own dwelling.

The Second Stage of the Qualitative Study – Characteristics of the Focus Group Participants

The survey participants in the focus groups were selected on the basis of a criteria-based selection, where sample units for one group were selected according to a predetermined specific criterion [56, p. 32].

There were three focus groups interviewed in this survey. Each group represented one criterion that was focused on the nature of a particular aspect of the research participants:

- **the first group** represented the educational sector; therefore, the key criterion was the employment of the survey participants in an educational institution;
- **the second group** represented the health care sector; thus, the research participants had to meet one criterion, which was to be employed in the health care sector;
- **the third group** was mixed – two survey participants represented the non-governmental sector, whereas six participants represented employers, i.e. the business sector. Therefore, the selection criterion was employment in the non-governmental sector or business sector.

The first group representing the educational sector consisted of the following ten research participants:

1. a deputy headmaster for education in a secondary school;
2. a health care specialist of the public health bureau (activity focus on the work with schools),
3. a social pedagogue in a basic school;
4. a teacher in a children’s home;
5. a form tutor in a basic school;
6. a deputy headmaster for education in a basic school;
7. a social pedagogue in a gymnasium;
8. a director of a family and child welfare centre;
9. a social pedagogue in a basic school;
10. a psychologist in a children’s home.

Three participants of the educational sector group had experience working with PLHIV.
The second group representing the health care sector consisted of the following eight persons:

1. a physician-venereologist in the Centre of Skin and Venereal Diseases;
2. a physician who is the head of health centre X;
3. a physician who is the chief specialist of the Information and Analysis Department of the Centre Y;
4. Head of the Project Department of the Z Project Office for the Baltic States;
5. a physician-infectologist working in a penitentiary institution;
6. a physician-psychiatrist working in a psychiatric clinic and university lecturer;
7. a physician who is the deputy director for medicine of a clinic;
8. a nurse specialist who is a deputy director for nursing in a clinic.

Four individuals from the focus group did not have any direct experience working with PLHIV.

The third group representing the non-governmental and business sectors consisted of the following six persons:

1. a scientist of centre Y of institute X;
2. a scientist of centre X;
3. a head of NGO Z;
4. a director of cafe D;
5. a manager of a private limited liability company R and businessman;
6. a manager of a private limited liability company T and businessman.
CHAPTER 3: RESEARCH METHODS
First Stage of the Qualitative Study – Individual In-Depth Interviews

Data Collection

In-depth individual interviews were used in the first stage. These interviews are designed as a dialogue between an experienced investigator and the informant which is aimed at obtaining important information that could be analysed [57, p. 9-10]. This interview was not intended to establish mutual communication and experience exchange, because the task of the investigators collecting information was to encourage the survey participant to open up by sharing his or her experiences. Twenty study participants (see a detailed description of the sample in Section “Sample”) were interviewed using this data collection method.

In this first stage of the qualitative study, individual in-depth interviews were used due to the following advantages [57, p. 10]:

- it allows for the collecting of much useful information and important details that often lead to new insights;
- there is visual contact with the informant;
- there is a possibility to examine a problem thoroughly;
- not only are the cognitive aspects of responses visible, but also the emotional aspects of responses;
- the investigator is able to clarify his questions, thus enhancing the possibility to obtain useful information;
- the investigator is able to communicate flexibly with particular individuals or under special circumstances.

The preparation for interviews was thorough:

- the interview questions were translated from English and validated (content validity) (see a more detailed description of the interview instrument in the section entitled “Research Instrument”);
- the interviewers were selected: three persons who have primary interviewing skills, are characterised by a high-level social competence and maintain social contacts with PLHIV, which facilitates access to the survey participants and enhances the possibility of conducting a study of good quality study because the participants feel safe and have confidence in the investigators, which forms mutually positive contact during the interview;
- all three data collectors were given a two-hour briefing on the interview specifics, the investigator’s behaviour, presentation of questions, time management, creation of a therapeutical atmosphere during the interview, sequence of questions of a concrete interview questionnaire and the possibilities of clarification thereof, uniform content presentation to the participants, and research ethics.

The duration of each interview was no shorter than 1 hour, and no longer than 1.5 hours (the average duration of the interviews was 1.25 hours).

When collecting data, the text of each interview was recorded with a dictaphone, then transcribed and entered into separate computer file while maintaining the confidentiality and anonymity of the interviewee.

The volume of all twenty interview texts (only the interview text, excluding the questions asked by the investigator) ranged from 8 to 21 pages in A4 format, when the text on each page had a font size of 12 pt, with 1.5 line spacing (taking into account the volume of the entire research sample, the average length of one interview is 12.85 pages).
Data Analysis

The method of qualitative content analysis was applied during the analysis of the qualitative data collected during individual in-depth interviews. Qualitative content analysis allows for the avoiding of superficiality when analysing the text [58]. The material of qualitative content analysis consists of the text received using different techniques, for example for interviews, and non-standardised questionnaires containing open-ended questions [59]. Mayring (2001) indicates that content analysis is a valid method enabling one to make specific conclusions based on the text being analysed [60]. Content analysis is aimed at identifying [61]:

- how this phenomenon is perceived / understood by the respondent reflecting on his or her experience, based on the questions asked by the investigator;
- what differences there are between the theoretical description of the phenomenon being studied and its expression in social reality;
- what the ways of the informant’s thinking and perception projected towards the research phenomenon are;
- what the possibilities and limitations are concerning the application of acquired knowledge, skills and capacities in an activity / social reality.

The text presented by informants is study material for content analysis revealing an individual’s process of reflection.

Morse (1997) specifies the following key characteristics of qualitative content analysis [62]:

**Purpose:** to identify the main aspects of the research phenomenon.

**Study material:** the whole analysis is carried out in the context of a specific text.

**Significance of the study:** new aspects illustrating the research phenomenon are revealed, or the existence of the characteristics of the same phenomenon identified in other studies is validated.

**Grounding of results:** based on the content of the text being studied and its highlighted data presented in sub-categories and combining them into categories.

The following aspects of qualitative content analysis as a research procedure are distinguished [60]:

- **Research techniques:** the research technique used must be incorporated into a communication model; therefore, the most effective way is to use interview or non-standardised questionnaires containing open-ended questions.
- **Text “speaks”:** received texts reflect human experiences, attitudes, and feelings and concretize the context.
- **Analysis rules:** the text content must be analysed consistently, step by step, according to the rules of a particular methodological procedure, and by dividing the analysed content into analytical units.
- **Categories and subcategories are the essence of content analysis:** the text is interpreted on the basis of survey questions to which answers are provided through formulated categories.

Qualitative content analysis is based on interpretation; therefore, the distinguishing of categories and subcategories is not an automatic, mechanical technique but a creative interpretation process aimed at decoding the meanings contained in the text [60].
This means that qualitative content analysis may be defined as an empirical, methodological textual analysis carried out within the framework of texts, based on the methodologically justified steps of the analysis.

In the analysis process, it was sought to avoid the formation of preconceived theoretical definitions and descriptions.

**Steps of the qualitative data analysis [61]:**

1. Selection of the unit for textual analysis describing the completed thought on the action, process, experience, understanding, etc. (part of the sentence, sentence, paragraph).
2. Multiple reading of the interview text.
3. Open encoding of the selected textual units by highlighting the main thoughts expressed in a particular textual unit.
4. Comparison of open codes by discovering identical and different codes.
5. Selection of different codes.
6. Grouping of codes linked by a common thought or idea into subcategories.
7. Grouping of categories into categories by a common idea linking them, for example, process, action, experience of the research participants, etc.
8. Presentation of categories, subcategories and group interview texts proving them in tables.

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**Second Stage of the Qualitative Study – Focus Groups**

**Data Collection**

Two investigators participated in each discussion. One of them was the main investigator who stimulated discussion and asked the primary questions as well as additional questions. The second investigator was an active observer who engaged in the discussion when he noticed temporarily reduced attention and fatigue of the main investigator.

Before starting a focus group discussion, two investigators said that when working with a group of the survey participants, it is important that each investigator participating in the collection of qualitative data is attentive and remember the main thoughts expressed by the respondents in the course of speaking (this helps raise additional questions or go deeper into the main questions that were asked); friendly and ready to help, ready to help the survey participants feel free; able to listen rather than speak for the respondents; feel the dynamics of the discussion and recognise the psychological features of people so that the investigators can manage the audience and lead the discussion in a more efficient manner; able to get an insight into the problems of opinions expressed by the survey participants and summarise it to the whole group. In the course of the discussion, the opinions expressed by each group were recorded with a dictaphone; later the text was transcribed and entered into separate files on the computer (according to the three groups).

**The stages of each group discussion were as follows:**

**Preparation:**

(1) the objective of the discussion was formulated;
(2) the time and venue of the discussion were chosen;
(3) the preparatory works were carried out: the premises were chosen, which included a table with chairs placed around it; no equipment which would disturb the discussion was in the room, the door of the room was not opened by those outside the room, and mineral water was purchased for the survey participants and the investigators;
(4) the guidelines of the discussion were chosen, which were comprised of specific questions depending on the focus groups:

a. two groups of questions were presented to the educational sector group: the attitude towards PLHIV and the situation of PLHIV in the educational system (in Lithuania);

b. three groups of questions were presented to the health care sector group: the general attitude towards PLHIV; attitude of physicians to PLHIV; maintenance of confidentiality; involvement in the work with PLHIV;

c. three groups of questions were presented to the non-governmental and business (represented by employers) sector group: the general attitude towards HIV-positive people; the situation of PLHIV in the labour market; the possibilities for professional development of PLHIV.

(5) the technical condition of the dictaphone was checked, and pens, large pieces of paper and A4-format paper were purchased for stimulating discussions among the research participants and recording the reflections after the session.

Conducting the discussion:

(1) the investigators introduced themselves to the survey participants, presented the objective of the survey and the issue, and indicated what kind of study was being carried out and for what purposes the obtained survey data would be used, which helped create a safe environment for the research participants;

(2) the investigators presented the structure and duration of the group discussion;

(3) the investigators explained the principles of research ethics to be observed during the entire survey to the study participants;

(4) all study participants signed a document on the maintaining of study anonymity and confidentiality, which was drafted by the project team;

(5) it was emphasised to the research participants that there were no right or wrong answers; therefore, all the answers and opinions expressed by the informants are important;

(6) during the group discussion, the moderator of the group discussion (the principal investigator) ensured that there would be no deviation from the main theme of the discussion;

(7) disagreements in group discussions on one or another issue were used as additional points of reference for streamlining the problem.

The investigators were observers and stimulators of the discussion among the survey participants. In order to create the kind of conditions where expressive and active participants would not dominate or become leaders, conditions to express their opinion were provided to introverts who find it hard to voice their views. This methodological strategy for collecting interview material allowed for the ensuring of participation by all group participants in the discussion.

Finalisation of the discussion:

(1) unclear questions were clarified to the study participants, and conditions were created for each study participant to give a summary;

(2) the investigators positively summed up each group discussion and thanked the study participants.

Post-group discussions:

(1) the investigators verbally reflected on each session of the group discussion, which include their feelings, behaviour, mistakes and “successful” positive moments in the work with respondents in each session of the group discussion;

(2) both investigators listened to the opinions of the study participants voiced during each session of the group discussion and transcribed them by discussing their personal reflections on the thoughts expressed by the respondents;
(3) the interviews of each group session were entered into separate computer files.

**Data Analysis**

The data collected in the focus groups and transcribed were provided in separate computer files adhering to the principles of confidentiality and anonymity, and were analysed by qualitative content analysis.

Please find the description of the method in the section entitled "Data Analysis" which is given in the description of the first stage (individual in-depth interview) of the qualitative study.
CHAPTER 4:

RESEARCH FINDINGS AND THEIR DISCUSSION
First research stage – in-depth interviews

The individual situation of PLWHIV: common personal understanding, perceptions and experiences

What does it mean to be HIV-positive? The phases of realization reflected in the speaking of the study participants are as follows:

- the first phase – upon learning one’s diagnosis, an individual experiences emotional shock, and therefore, it is concealed from the environment. The interviewees have a preconceived attitude that the majority of society is hostile to PLHIV. For this reason, they are not inclined to discuss their problem with others. They experience emotional shock, huge stress, panic, or depression;

- the second phase – after some time an individual gets used to the current situation and little by little opens up to others. However, first of all, a person must realise the importance and meaning of this HIV diagnosis for his or her life. A person comes to terms with their current health situation.

The experiences of a person who has been aware of their HIV diagnosis for a long time differ from the experiences of an individual who has been aware of this diagnosis only for several days: a recently diagnosis of HIV has not disrupted the person’s life rhythm and there are no experiences related with public stereotypes. However, every new day brings more and more contemplation and anxiety for this person. This is why one of the study participants’ claims that “old” dreams had to be deleted from his life and strength has to be found for contemplating “new” dreams and different life goals. There were thoughts about returning to drug use. Thus, PLHIV try to “tame” their life situation determined by HIV diagnosis and rethink their life values, on the basis of which they form new life goals.

The respondents state that they constantly reflect on their life situation: is it worth opening up to others regarding their health situation because they can be rejected, or are there any possibilities of starting up a family? They contemplate these things on a daily basis, and this often exhausts a person because this kind of life is characterised by constant tension and anxiety.

The study participants claim that they feel “exceptional” not in terms of self-value but rather in terms of their life situation determined by the HIV diagnosis: they must protect themselves and others and they cannot be fully relaxed as earlier, before the diagnosis of HIV. This means that the self-empowerment to assume responsibility for themselves and others in terms of prevention creates preconditions for living under a conscious and constant emotional tension, and thinking continuously about what and how they do things. Therefore, an HIV diagnosis also means constant regular use of medicines and a self-empowerment to use them.

The interview participants claim that an individual does not live on his or her own; therefore, they must pay attention to their new needs and the needs of their friends, to think about the safety of their friends and not to disregard public attitudes. Thus this “new” adaptation becomes a conscious process. The PLHIV state that it is difficult to discuss HIV with others because they feel “cursed” and experience public condemnation and hostility.

What does it mean to live with HIV? What does it mean to other people? The study participants emphasise different public attitudes concerning PLHIV. In this context, the link is revealed between the existing attitudes of society towards HIV / AIDS and their preconceived attitudes related to HIV in a general sense, and more specifically to PLHIV. Based on the survey results, a presumption can be made that the interview participants correlate the concept of “perception” with the concept of “information”. 
For this reason, there is an obvious tie between the information possessed by society and existing attitudes, which are often negative, and alienate HIV-positive people. The study participants openly state that HIV is a deadly disease for society, and many people are afraid of even touching those that are infected.

The outcome of the data analysis revealed that a lack of information prompts not only social but also psychological exclusion of PLHIV: having no accurate information, the “healthy” consciously avoid communicating with PLHIV, or experience fear, for example, where one has to extend a hand to an HIV-positive person when giving greeting, or has to sit at the same table. For PLHIV themselves, the changed health status first of all means the protection of people surrounding them from the potential transmission of HIV.

The survey participants believe that the possibilities of the public to communicate with PLHIV, to listen to their experiences, and to receive information about the ways of transmission from them are more effective than other means of providing information, which include for instance only theoretical lecturers, and booklets with fragmented information. However, the interview participants recognise that they often come across “a wall that is hard to break through” [study participants (1) A, (4) D, (5) E] due to the non-awareness of the public at large. The latter aspect is a clear precondition for the social exclusion of HIV-positive people.

The participants have a positive opinion about educational programmes which allow PLHIV themselves to get to know their health situation better, while simultaneously serving as prevention against large-scale problems and mental disorders caused by constant tension and self-remorse. Some research participants accept the HIV diagnosis as a fact and that living with HIV is a natural part of life for them (“you cannot do anything about it… it is like it is” [study participants (4) D, (7) G, (8) H, (13) N]).

It is clear from the statements of the respondents that HIV diagnosis was and is the reason for their state of constant tension. Only some of them are capable of concealing this and dealing with psychological tension, whereas others are inclined to convey their anxiety and suffer emotional tension expressively. Tense situations occur when the research participants ask medical specialists for information about other diseases as if denying that HIV is more complicated than other diseases, for example, information about hepatitis B or C. This kind of self-comfort is one of the self-management strategies when living in a situation where one’s state of health is determined by an HIV diagnosis.

The respondents claim that after the diagnosis of HIV, a person “withdraws to his or her world” [research participant 16 R], while many of them experience a mutual, double withdrawal – the person living with HIV withdraws from society and society distances itself from the person with this disease. This shows that society is not ready to accept PLHIV and reveals an HIV-positive person’s psychological defence by withdrawing from external social contacts.

**How are PLHIV perceived in society?** One of the research participants claims that he has not experienced negative public attitudes yet, but has heard about the existing stereotypes. The participant himself was and is in an environment where the majority of persons are infected with HIV, but he used to “push away” the thought that he might get infected himself, even though he was leading a risky lifestyle by using drugs.

The respondents consider the lack of information about HIV / AIDS to be the key obstacle which allow for the entrenching of negative attitudes and behaviour prompting exclusion. In the course of analysing data, it has become obvious that the non-awareness of the public stimulates the development and deepening of stereotypical attitudes: the public tolerates persons with tuberculosis and hepatitis, though those are more dangerous diseases (particularly their last stages) than HIV; however, society “punishes” PLHIV with its negative attitudes and unambiguously and mainly associates this diagnosis directly with people from risk groups. The interview participants claim that they are better understood within the medical
community and, in a general sense, are not understood in society due to the ignorance and non-awareness of people. This low level of awareness in its turn causes humiliation, injuring the personal dignity of PLHIV; for example, fear to greet someone, or to communicate. Having received information, some people change their behaviour in a positive way after some time. Thus, the understanding concerning PLHIV is an outcome requiring a long period of time and the dissemination of accurate information from medical specialists and PLHIV themselves.

The experiences of some research participants are linked to silent compassion and pity by their environment. Thus, the environment seeks to protect a person living with HIV from negative experiences at least emotionally and psychologically.

The research participants emphasise that society condemns HIV-positive people; thus they have having “been marked with a label of HIV” [research participants (9) J, (14) O, (17) S], and avoid talking openly about their situation because such a person is “condemned” in society.

One of the study participants states that the stereotypes existing in society are linked to the need to “punish” people for the failure to comply with the moral norms in society, for instance, if a homosexual person became infected with HIV, then a “double” punishment is imposed, i.e. a person experiences “double” discrimination:

Stereotypes. I think that society is quite tolerant in general. There are people who associate HIV with drug addiction, homosexuality, etc. There are some who do not condemn people with HIV… it can be said so… If there was a spread [of it] <...> genetically, inborn? But the ways of HIV transmission are clear, through blood, sexual intercourse, etc. And they associate this with homosexuality, they hate homosexuals and hate those that are infected because there are some among them <...> double discrimination <...> That they hate the infected person her or himself, not because of the infection but because of the ways of it that are associated with every infected person… Although there are many various ways of transmission, even such cases where having simply succumbed to passion, a person <...> has made love to his or her loved one and did not even know that … Maybe the person who transmitted [the infection] did not know himself or herself because there is the window period… And a person might have done a test but the tests have not showed anything and in fact he might be already infected. [research participant (20) V]

What are the differences between HIV-positive and HIV-negative people? The outcome of the qualitative data analysis revealed that after a person has been diagnosed with HIV, he or she experiences limitations on his or her relations with the environment: some people in the surrounding environment totally turn their back on them and do not want to keep in touch, while the attitudes of some people change cardinally (which also means a reluctance to communicate), and often an HIV-positive person is ignored.

The research participants emphasise the difference between the age groups – the younger the male, the greater the need is for sexual relations, which may cause negative consequences by getting infected with other diseases. Therefore, there must be a conscious assumption of responsibility for the protection of one’s own health by limiting the quantity of sexual activity and looking after oneself so that no other accompanying diseases are acquired, because the latter obstruct the course and treatment of an HIV-positive person’s primary disease.

The research participants state that there is a direct link between telling about one’s HIV and social exclusion because when people do not know that the person is infected, they act as they usually do, but after they have found this out, they turn their backs, and the HIV-positive person becomes “second-class” [research participant (4) D]. The interview participants claim that there is no difference between the “healthy” and the “ill”; however, the initiatives of HIV-positive people themselves to share their experiences and tell the public about themselves and their personal experiences have a great impact. Other study participants supporting the opinion that there is no difference between the “healthy” and the “ill” claim that this difference is eliminated by needs. The research participants indicate that there is no difference between
the “diseased” and the “healthy” in a public or external and internal or personal sense: they have the same desires, needs and dreams. However, PLHIV must limit themselves with regard to their own health and the health of others. Therefore, the psychological differences between PLHIV expressed as the deservedness of these persons may be distinguished in this context:

How normal I used to feel, the way I felt earlier while I still was not infected. I was not afraid that I might be pushed by somebody, or that somebody would say something. There was nothing for others to find out, a person living a regular life. If there is something now, I try not to talk about it with anybody. There are exceptions to whom I can say that I am infected, usually I do not talk about this. [research participant (16) R]

The results of the data analysis have revealed that an HIV diagnosis places certain limits on an individual: one must distance himself or herself from people who go to parties because they often use alcohol there, and a state of intoxication may cause a fight, the consequences of which may be unpredictable. For this reason, the respondents claim that they must substantially change their lifestyle. One of the interview participants indicates that life without HIV is a temporary thing for persons using drugs: people who use drugs hurry to inject them and their impatience often lead to the use of used syringes. Thus, the assumption of responsibility for the protection of one's health is an important moment.

After an individual has contracted HIV, the joy of life is lost and he or she lives in anticipation of the transformation of HIV into AIDS, i.e. a person lives under constant tension regarding the future and the present of his life. Many survey participants did not contemplate the meaning of life before they had contracted HIV and treated life as a game. Only now have they understood that their dreams, anticipations, desires and their implementation have strong limitations due solely to the HIV diagnosis. And what happens if there is also drug addiction and alcohol use? 

<...> big differences. If an infected person lives a normal life, is not a drug addict and is not dependent on alcohol, then he may have a normal life, achieve something in his life and not to waste it in vain. Before I got infected, I had lived day to day without ever thinking about this.[research participant (17) S]

By openly stating his opinion in the interview text, one research participant created preconditions to think that HIV-positive persons must be and are people with an exceptional status in society – they do not pose any threat or danger to society, whereas society poses a threat to PLHIV, for example, persons who are ill with other diseases in the environment may transmit these diseases to PLHIV. Such thoughts are controversial: on the one hand, the interview participants voiced an opinion that they do not want to be exceptional and are capable of protecting the environment and themselves by assuming responsibility for the quality of their life, while on the other hand, they expressed an opinion which clearly shows that HIV is deemed an “ordinary” disease which could be a norm, while society itself must protect PLHIV.

The interview participants state that life in a health situation determined by an HIV diagnosis is complicated by psychological tension and discomfort, for example while communicating, talking, and walking, among other things. If a person has no possibilities to talk to others about this and does not disclose this even to his or her closest family members, then this is self-destruction in a psychological sense:

<...> you destroy yourself psychologically: you hide from everybody <...> you should not conceal it in this case. An infected person is inhibited. It is very hard for him psychologically. <...> some do not say this even at home... and the majority do not tell anything to their parents <...> because they want to protect their mother from any stress <...> or their father or any other close person, and they must live under constant tension. Psychologically, this is very hard. This <...> leads to a person’s alcoholism or those who do not use any psychoactive substances start taking sedatives <...> this causes people who have not even been like this <...> to become like this sometimes...[research participant (20) V]
From the words of one of the interview participants given above, it is obvious that an acceptance of HIV diagnosis often means emotional shock for a person. If a person has no possibility of receiving psychological and moral assistance, there might be some problems which have not existed prior to HIV diagnosis, for example, a dependence on drugs or alcohol. Thus, HIV diagnosis may become a precondition for people to acquire dependencies and have a negative effect on their lives, unless they receive timely psychological support.

What and how did your life changed after you have found out that you were diagnosed with HIV? The respondents confess that each day is full of anxiety, because they cannot plan their future, as they simply “are never sure about tomorrow, what will happen tomorrow” [research participants (6) F, (11) L]. Many study participants stated that immediately after the diagnosis, they went along a complicated path

<table>
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<th>Table 3. Differences between HIV-Positive and HIV-Negative People</th>
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<td>Correlations between the age of PLHIV with the need for sexual relations</td>
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<td><strong>Non-existent difference between the healthy and the diseased</strong></td>
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of contemplation, orienting themselves towards the environment they live in: it is not clear what the reactions of their close ones, family, acquaintances or friends will be after they have learned the diagnosis. Knowing information on HIV and psychological consultations encouraged them to inform their environment. Some interview participants claim that they do not see any differences in their life before and after the HIV diagnosis but they are constantly contemplating and living in self-empowerment, not to return to the negative lifestyle, and find strength to change their life. The research participants said that their life must be changed radically: thinking, decisions, behaviour, and negative life habits. It is hard to do this because one needs moral strength and tremendous motivation to assume responsibility for one’s life.
Having found out about their disease, people worry not so much about themselves as they do about their close family members and particularly about the obligations they had accepted before the diagnosis.

They are particularly frightened of financial obligations, for example the repayment of loans.

Following the diagnosis of the disease and feeling uncertain about their future, PLHIV on a daily basis experience anxiety and tension, not wanting that their problems would be transferred to their family members or that someone would have to take financial obligations on behalf of the HIV-positive person.

One of the study participants said that after having found out about his diagnosis, first of all he purchased more condoms in a pharmacy – this was the first change in his life. Now, after some time has passed, he considers it to be a consequence of the emotional shock and immense stress that he had experienced.

The results of the data analysis revealed that the satisfaction of physiological needs of the majority of the interview participants has not changed – they remained the same as when they were “healthy”. However, sexual relationships changed, for example with one’s wife. In addition, a need for self-protection has arisen when communicating with others – “so that others would not understand” [research participant (8) H] – as a conscious form of concealing information in fear of being psychologically or socially separated from the environment. In addition a responsibility for others has appeared. For example, if they cut their finger, they try to fix it themselves so that there is no blood left on any surface and no other people would come into contact with this blood.

Before they had been diagnosed with HIV, blood donation was a usual practice for some survey participants. After HIV has been diagnosed in the blood centre, the motivation to not use drugs and alcohol appeared (though not immediately).

There are some research participants who have accepted the HIV diagnosis calmly because they were consciously taking drugs, i.e. they were aware of information about the consequences and possibilities of getting infected, but they still used drugs though they did not use the syringes used by other people. The interview participants who are still active drugs users today have a stronger anxiety about getting infected with hepatitis C rather than living with HIV. HIV-positive people often read literature on various diseases and refer to the arguments published by scientists in scientific articles on hepatitis and HIV complications, compare these diseases with each other, and calm themselves down that there are “even more serious diseases” [research participants (1) A, (2) B, (3) C, (5) E, (9) J, (12) M].

Several interview participants live in a partnership with a person who is infected with HIV as well.

The interview participant states that HIV was first diagnosed to her partner – she helped him live through the emotionally hard period. Having such an emotional experience, she became stronger psychologically. Later, when she was also diagnosed with HIV, this news did not cause any emotional shock – it was hard but she did not lose the desire to live.

Some study participants had the will to withdraw from the use of drugs and start living a healthy life.

The disclosure of HIV infection has controversial consequences, and one of them is that most often people that are closest to those infected start communicating only formally, “at a distance”.

Some research participants consciously distanced themselves from external communication – they do not contact others and others do not contact them.

One of the survey participants states that distancing oneself from others is not a rational path. Even though it is hard, one must empower oneself to live a positive life by taking interest in the life, activities and associations of other HIV-positive people,
participating in meetings, etc. It is not easy to say “stop” to one’s former life and “stop” to inactivity, and to “start” a new life by obliging oneself to live DIFFERENTLY:

There was a period when I thought that I must cut off relations with everyone and then the problem will be resolved; there will be no need to tell anybody. I stopped communicating with everybody <...> If somebody called, I would say “I have no time”<...> Later I felt the need to communicate. I did not have anyone to communicate with. <...> and I started to look for communication, and how do you look for it? Well, practically that’s clubs <...> parties, and you come and drink some alcohol <...> “friends” appeared <...> I stopped in time, I thought - where I am going and what kind of friends are those? Those were not friends but rather some party companions and that’s it. They were not friends. And then I said to myself “Stop”. <...> a cardinal change was when I started to think: “I am not the only one like this” <...> then I started to take an interest in organisational things <...> activities carried out in other countries [in countries both nearby and farther away] <...> I started to learn English <...> if one has to carry out an activity, he or she must know the basics of management. I started <...> to take interest in that. <...> knowledge of accounting and organisational matters was needed <...> I broadened my horizons, started to take interest in that, and to learn. <...> my life has changed for the better. But I understand that there are only a few people who can start doing something on their own. [research participant (20) V]

How did you find out about the HIV diagnosis? The data analysis revealed that people find out about their diagnosis by accident, and it often has a negative impact on future relationships between partners.

According to one survey participant, when he was in prison, he underwent tests for diagnosing HIV but the infection was not detected. After he has left the penitentiary institution and found a partner who used drugs, the latter received an SMS message from a close one stating the penitentiary where her partner served his sentence and that HIV cases were detected in that particular penitentiary institution. Then the partner, i.e. the ex-convict, himself encouraged her to go and check her health. The diagnosis was merciless – hepatitis B and C and HIV. But the partner was healthy. After the diagnosis the relationships between the partners did not last for a long time (for six months, and then they broke up); however, the partners felt the responsibility not to get infected – they avoided using drugs.

The ways of diagnosing HIV are different: some persons decide consciously to come for a test, others were diagnosed in a blood centre, detoxication clinic, or when participating in a methadone programme. A few research participants were diagnosed with HIV while in the hospital for an overall health check. There are some cases where study participants found out about the diagnosed HIV in several stages, for example, their blood was taken when they were hospitalised, and they received the diagnosis in the penitentiary.

What do you do differently now after the HIV diagnosis? The research participants do not deny that it is complicated to live with HIV – many of them experienced reservedness, or a reluctance to communicate or talk to anybody because they are overtaken by the panic over their current and future life. For some interview participants, the first months after the HIV diagnosis were as usual, with HIV diagnosis like a “cold”; therefore, they continued to use drugs giving their syringes to others or injecting drugs with syringes used by others. Only after some time they started to read more and deepen their knowledge, and, finally, they realised the extent and complexity of the problem and their situation.

The changes following HIV diagnosis are varied: pragmatical, such as only safe sex, and emotional, such as shock to tell the physician about the disease and to go to the AIDS centre. One of the study participants revealed the dynamics of changes in the relationship with the partner: “you are afraid to say, so you start restricting yourself and avoid relationships” [research participant (4) D]. These aspects are internal, psychological, causing tension and creating a precondition for the person to distance himself or herself from their environment.
After the diagnosis, those with HIV discovered life anew: they learned to be happy about small things and empowered themselves to take an interest in different fields. After the diagnosis, HIV-positive people started to look differently at complicated life problems or situations – now they find it easier to live through them and deal with their emotions, feelings, and reactions. This allows one to presume that the perception of the complexity of one’s situation is compared with temporary problems in life and are not exaggerated, as it could have been the case earlier before the establishment of the diagnosis. After the HIV diagnosis, life took on a different meaning for many survey participants – they reflect more serious on their place under the sun; they do not make unrealistic plans and start appreciating life as a value. The HIV diagnosis substantially complicated the life of some respondents in such situations where a decision was made to withdraw from the use of drugs or alcohol by doing such things as visiting specific centres, and working with themselves among other things. Being diagnosed with HIV was one of the preconditions to return back to their former lives. Thus, in such psychologically complicated cases as being diagnosed with HIV, a person needs a huge external stimulus motivating one to live. The birth of a child served as such a stimulus for one of the female study participants, and she has seen her life until today as devoted only to her child and the child’s future:

<...> I cannot say that the HIV diagnosis changed my whole life. But it changed in such a sense that... I don’t know... the desire to live has emerged... First of all. I thought how so? I had just started to live and such a diagnosis, as if some cross has been put upon you – the HIV infection. You complete the rehabilitation course, I was so happy.... you become free from drugs, new thoughts, new plans... and I don’t know as if a cross has been put upon you... There will be no family, no such plans in my life... Thank God that I have a child and... I think that I will live those years that have been given to me for my child... [research participant (17) S]

PLHIV are not unanimous concerning informing their family. For example, one of the research participants states that he has not informed his parents yet because they are elderly, and they are from a village and still live there (having no knowledge and positive information) and are in poor health; therefore, this kind of information could cause them a lot of emotional pain and anxiety. As a result a decision was made to keep silent. However, silence has its price in an emotional and psychological sense: it is hard to keep this only to oneself. Therefore, a need arises to attend events held for people of the same fate, where problems can be voiced openly and potential solutions can be discussed. The study participants repeat themselves claiming that an open statement about HIV diagnosis is a precondition for rejection in society. This is linked to those closest to them (friends) and society in a general sense (one of the research participants was put in a detainment facility, and was refused a haircut only due to his HIV diagnosis). For this reason, they live on the basis of preconceived attitudes, for example they are afraid to search for a job because they are certain that they will not get it – a health certificate is needed, and then the diagnosed HIV will be disclosed, which will cause them not only to be refused a job but also other negative consequences in society. Therefore, one of their self-protection strategies is withdrawal from social relations with society, i.e. to communicate with the environment only in exceptionally urgent cases. However, this decision was determined by specific experiences when society deprived them of their personal dignity:

This happened in my yard. I can give an example. I don’t know how but my neighbours found out that I am sick, how I and where I received an apartment but somebody on the door of my apartment… I think that one of my acquaintances wrote in capital letters: “Beware, someone infected with HIV lives here” and they wrote my name as well. And people started to look at me differently... some of them were afraid to touch me. I understood that people are afraid of me, they were afraid to go by lift, and that’s how I closed up in myself... I go out when it is getting dark; I do not go out during the daytime in general. I try to walk less because there is a bench in the yard and people tend to gather there... they do not let me pass with their eyes, glances... you can hear how they talk about you.. They made me to understand that, and I
closed up in myself... I started to use more alcohol. I am tired of carrying all of this...
Just like with a family; you get tired, go to the balcony and close the curtain so they
would not see you, that's it... [research participant (16) R]

The exceptionally negative attitudes in society cause great tension for PLHIV and
thus create preconditions for them not only to withdraw from external social rela-
tionships but to return to their negative bad habits, to use alcohol or drugs but in
larger doses consciously so that “all this would end faster” [research participants (3) C
and (12) M]. HIV-positive persons who have spent several years in penitentiaries and
are active drug users have a clear decision regarding the end of their life – they do
not want to become a burden for others and are not afraid to recognise that they will
leave this life on their own after HIV complications have started. Some PLHIV start
leading a totally closed life, for example, the woman whose partner is also infected
with HIV communicates only with him after she has been diagnosed with the same
disease. This means that the diagnosis sometimes creates preconditions for indi-
viduals to totally withdraw from their environment without feeling any discomfort
because the infected partner creates conditions for psychological survival.

Who knows that you have been diagnosed with HIV? The research participants
are not inclined to inform about the diagnosed HIV persons with whom they do
not have close relationships, who have become distant to them and with whom
they do not communicate. Those can be family members, for example sisters or
brothers. However, the majority of HIV-positive people feel a responsibility for those
closest to them – they informed their friends immediately after the diagnosis of
HIV. Where one of the study participants experienced a drug relapse, he informed
his co-users of the diagnosis of HIV as well.

The majority of the research participants are honest with those closest to them.

For example, when receiving treatment in the rehabilitation centre, study participant
(2) B informed his community about the diagnosed situation. In this context, the
sensitivity of the research participant (2) B towards his family is revealed: he found out
the diagnosis at an unfavourable time, during a funeral, and decided to inform his family
later, i.e. was looking for a favourable situation. The decision was clear – the HIV-positive
person mentioned the day when he will inform them, but will do this in the presence of
the leader of the rehabilitation group who will be able to inform the family members in
greater detail about HIV, treatment and the consequences, and reply to other questions
that are of concern to the family.

This context reveals that PLHIV who are aware of their situation experience stress,
anxiety, and fear. Often those HIV-positive persons who participated in the research
have a clear position – to inform only the closest environment and their family
members about the disease, however they are not inclined to inform distant rela-
tives or persons with whom their communication is irregular because they do not
see any sense in it. When PLHIV have a family – a wife and children, an important
decision to inform them about their health situation must be taken. The study par-
ticipants told that many have informed their family members after the diagnosis
and received understanding. When analysing, it became clear that the support of
family members depends on their awareness, knowledge and reading about HIV/
AIDS. Children often experience initial emotional shock but later they come to terms
with the situation because the feeling, that this is their father/mother, overcomes
hostility or coldness. Friends are informed later. Only the very closest ones whom
the individual has known for many years and trusts are informed.

Some research participants inform only one member of the family, for example their
mother, but they provide information to read before disclosing this information.
This method of disclosure has a positive impact and prevents an individual’s social
exclusion within the family. However, many respondents consciously do not inform
their more distant family members. For example, the stepfather is not informed
because there is a fear of rejection expressed in concrete actions, such as being
kicked out of their home.
The study participants state that informing children about HIV is complicated – it is worth talking only when a child is older and can understand what you are saying. However, even after the family has been informed, conversations on the subject of HIV are avoided, as they are taboo:

*No, we don’t talk about this subject anymore. I had to explain <…> when [the child] heard from somebody and said how [the child] defended me. And I explained everything, what and how.* [research participants (11) L and (16) R].

The given example shows that information about the family member’s infection with HIV is first obtained from external sources, and this is a negative experience for both family members and the HIV-positive person.

The lack of knowledge about HIV or solely negative knowledge of family members creates preconditions for rejection or coldness towards the infected person in communication.

*Having solely negative information about HIV, the mother does not seek to help but just tolerates the diseased (“Does not kick out of home, and this is already good” [research participant (1) A]) and does not conceal her fear, for example, she is afraid to touch her son’s hand and is scared of his touch or hug.*

There are some research participants who consciously conceal the HIV diagnosis from their partners because they know the persons with whom they live well: they recognise their categoricalness but are afraid to lose them, to ruin the relationship, and are fearful even of blackmail with the help of the police or detention facility.

It is obvious in these stories, people with HIV that are in environments that are unaware of their infection try to behave in such a way that their environment is not able to decipher their health status.

*For instance, if an HIV-positive person cuts oneself, they fix everything themselves and do not allow anybody to touch their wound because they want to protected others from contact with their blood. Thus, the feeling emerges of immense responsibility for the environment and not infect others.*

The reactions of colleagues are different: when there are no external factors or events, everything is the same, but when there are extreme situations, for example, the cutting of a finger, where help is needed, the emotional harshness of colleagues becomes apparent in this context, which goes so far as going to the employer with a request to dismiss the person because “he is a walking bomb”. Reactions are spontaneous, but not angry, as can be seen from situations where colleagues apologize for emotional outbursts but this context shows that information about the HIV-positive person in the work environment creates preconditions for others to experience anxiety and tension that is suppressed. Many of the survey participants had to go through the experience of negative things after they have informed their friends about the diagnosis of HIV: after they have opened up, the relationship was ruined, communication was cut off, and the “informed” person started to spread rumours. One of the research participants openly said that his infection is treated controversially by friends whom he communicated and used drugs with before the HIV diagnosis: friends do not pay attention to the information about the disease he constantly says, but think that he is reluctant to share drugs. This shows that any honest information has little to no impact at all on drug users until the find themselves in the same health situation. One of the study participants who are currently using drugs, has warned friends closest to him and thinks that this is enough. This means that when another person injects drugs with the same syringe, this is the responsibility of that person, because he had been warned before. Some of the respondents have deliberately distanced themselves from their environment so that they do not need to inform anybody about the diagnosed disease: when there is less communication and no questions, one does not have to experience tension regarding answers and suffer stress-causing reactions from one’s environment.

An opinion was often expressed by research respondents in their replies that the diagnosis of HIV is a normal thing. However, they do not provide more detailed
comments on this phrase. Further qualitative research is needed to carry out an in-depth investigation of this concept.

**How has your behaviour with other people changed now? Who has helped you in this situation?** After a person has been diagnosed with HIV, his or her personal responsibility for persons with whom he or she has sexual relationships increased. In particular, the research participants emphasised that they try to protect partners who do not use drugs. Thus a consciousness appears after becoming infected with HIV.

The study participants stated that their behaviour has not changed with their close environment. However, the community they are in has experienced shock: the first reaction shocked others, first of all because of the person’s openness. Many members of their community stated that they would not have the strength to openly tell others about the diagnosis and most probably would return to their negative lifestyle using drugs. Thus, the data analysis has revealed that the positive support of one’s close environment, which means understanding, is one of the most important factors for an HIV-positive person increasing the motivation to live differently, to fight for his or her health, and to overcome bad habits.

HIV-positive persons stated that even thought external communication with the environment has not changed, many of them consciously set new limits on aspects such as their communication and lifestyle, among other things having found out about their HIV diagnosis, individuals tend to strongly control themselves when communicating with the environment, i.e. when talking to others they think what they are saying so that they do not reveal their state of health. Some study participants consider the deliberate distancing of themselves from their environment as one of the strategies aimed at protecting themselves psychologically and socially.

For example, one of the study participants stated that her brother used to restrict communication between his children and her and would not let them touch her and the HIV-positive person felt immensely humiliated; and thus, she decided to strongly limit their relations.

Caution in communication is associated with a situation where an HIV-positive person communicates with the “brothers of fate” – it is important that confidential information is not disclosed because it is then that the aspects of honour and dignity are touched upon. The diagnosis of HIV changed the attitudes of the research

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<th>Category</th>
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<td><strong>Personal responsibility for not infecting other persons</strong></td>
<td>Personal responsibility for not infecting one’s partners</td>
<td>&lt;...&gt; the only thing that’s changed is that I have to see with the girls, you know, I am afraid to infect them, only in that case.</td>
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<td></td>
<td>Personal responsibility for not infecting one’s partners</td>
<td>&lt;...&gt; there is a greater responsibility, you think all the time how not to infect another person, particularly the one who is far from drugs, from all this in life.</td>
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<td>I became more careful with the blood, if I cut something, I cut myself pretty deeply, then I don’t come close to my child, I put on a band-aid so that I don’t infect others...</td>
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<tr>
<td><strong>Experiences of the rehabilitation community after they have found out about the person’s HIV infection</strong></td>
<td>Compassion of the community members for the HIV-positive person</td>
<td>No. There are people in this community who use drugs and they know that you cannot get infected so simply here. Perhaps the only change was on the first day right when I said this – there was compassion.</td>
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<td>Shock experienced by community members due to the openness of the HIV-positive person</td>
<td>A majority of the community was shocked. But yesterday, today... Everything was very intense on the same day. I said it and it was a shock right at that minute &lt;...&gt;</td>
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<td>Positive support of the HIV-positive person in the community by admiring his or her courage</td>
<td>&lt;...&gt; all of them went out and said: “oh, I don’t know, if I were you, I don’t know if I would have returned to the centre, if I have managed to find the strength to come back, maybe I would have given up everything and continued using [drugs]! Everybody praised how strong you are, like this and like that, and the relationships remained the same.</td>
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<tr>
<td><strong>Personal maturity by admitting their own health situation and the state of health of other PLHIV</strong></td>
<td>Maintenance of understanding, tolerance and dignity in relation to oneself and others</td>
<td>Maybe it has changed, really. Earlier I would also look: HIV, how they get infected and similar things but then there was less information than now, and when I knew everything myself, when it appeared in me... somehow... this is... you cannot change anything now... and I look differently at these people...</td>
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<td><strong>Unchanged communication with the environment</strong></td>
<td>Internal self-restriction</td>
<td>Everything is the same as it was. Personally I have set some limits, all kind of barriers and restrictions, for myself.</td>
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<td><strong>Changes in communication with the environment</strong></td>
<td>Self-control when talking to other people</td>
<td>I think more about what I say so that I do not blurt out something.</td>
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<td><strong>Silent rejection of the person who has confessed about his or her HIV infection within the circle of friends</strong></td>
<td>Estrangement from friends</td>
<td>(&lt;\ldots) I have recently told this to my new friends and girls. Maybe I am mistaken but I think that they have taken one step back to distance themselves. There is friction right away. Not even to parties... Or you sit next to them, and they move to the side. I feel that there is a lack of information and they avoid me.</td>
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<td><strong>Constant fear</strong></td>
<td>&quot;If they find out – maybe they would kick us out of the house&quot;</td>
<td>That fear, not everybody understands this thing after all. Maybe they would kick us out of the house, we don't know what they would do.</td>
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<td><strong>Deliberate distancing of family members from the HIV-positive person</strong></td>
<td>Cold and formal relations with brother</td>
<td>My brother found out ...he... he did not say anything specifically... I have just felt that there is a barrier between us. There is a barrier and my meetings with my nephews, his sons, became limited...</td>
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<td><strong>Behaviour of family members humiliating the dignity of the HIV-positive person</strong></td>
<td>Behaviour of family members humiliating the dignity of the HIV-positive person</td>
<td>I remember those cases when I was in the room... The nephews love me very much, and first of all, they come to my room... And that time they arrived and came to my room, and my brother with his wife almost caught them by their clothes and dragged them back, I was furious about this and felt so helpless that I almost cried... afterwards I noticed that I had started to alienate myself.</td>
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<td><strong>Complicated search for sexual partners after one becomes infected with HIV</strong></td>
<td>Partner’s constant fear of infecting others with HIV</td>
<td>It has changed, of course. It is much harder to find a sexual partner, for example. Practically, impossible. Because this fear of people is a natural human fear. The majority of people know they will communicate with you, hug you, kiss you, but only as friends in most cases. It must be really true love so that a person would not think already... and... still a drop of this fear remains. And therefore (&lt;\ldots) there is such a problem, most probably, for many people.</td>
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<tr>
<td><strong>Dilemma among HIV-positive people – “to say or not to say” – to their partner</strong></td>
<td>Why is there so much discussion among infected people whether they should find an infected partner or simply not to say anything... Not to say... of course, you may say nothing if you are sure that all this protection will protect (&lt;\ldots) And this is a very arguable issue of whether to say it or not. Although there are laws that you may be punished even for accidental transmission.</td>
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Participants towards other persons of the same fate – they have more understanding, tolerance and wisdom not to condemn, i.e. a need to maintain dignity. In this context, what is clear is the projection of one’s own situation onto another person encouraging empathy and humanity. Opening up in the environment of one’s friends may cause rejection – they often avoid being or sitting next to an HIV-positive person in parties. However, the study participants tend to justify these people appealing to their friends’ non-awareness and lack of knowledge about HIV/AIDS. HIV-positive persons discuss the issues of finding a sexual partner as well. In this context, they face the following dilemmas: “Should I say that I have HIV, because I will not be able to find a partner? Or not to say that I am infected with HIV but to use protection?”

It is much harder to find a sexual partner, for example. Practically impossible. Because this fear of people is a natural human fear. The majority of people know, they will communicate with you, hug you, kiss you but only as friends in most cases. It must be really true love so that a person would not think already... and... still a drop of this fear remains... And therefore \(<\ldots\) there is this kind of problem, most probably for many people. Why is there so much discussion among infected people
whether they should find an infected partner or simply not say anything... Not to say..., of course, you may say nothing if you are sure that all this protection will protect <...> And this is a very arguable issue of whether to say it or not. Although there are laws that you may be punished even for accidental transmission. [research participant (20) V]

Is it complicated to live with HIV? The study participants often claim that one can feel the complexity of living with HIV only during a longer period of time, but there are no obvious changes or difficulties in the initial period. Some of them live in a certain illusion, calming themselves down that HIV is not a complicated disease and one has simply protect himself or herself when using drugs (if a person is addicted to drugs) and then they will live long. However, it should be emphasised that the constant comparison of HIV initiated by the HIV-positive person with other diseases reveals the concealed subconscious anxiety and fear of a life with HIV.

There are two sides of the coin when living with HIV: life is not complicated, when we talk about contacting physicians, one has simply to decide whether to inform them or not inform them; life is complicated, when psychological and moral support is needed – often a person has to deal with complicated emotions on his or her own. Many study participants claim that life with HIV is complicated because one has to empower himself or herself to contact physicians and to carry out the exact treatment instructions of physicians. Often the respondents state that the first stage was treatment of alcohol and drug addiction. Thus, the overcoming of bad life habits is the manifestation of complexity in living with HIV as well.

When communicating with health care personnel, HIV-positive persons sensitively react to every word, glance, instruction, etc. However, the example given below allows one to presume that medical specialists must develop their social competences and emotional intelligence by learning not to express their categorical attitudes and frequent moralising. This does not help HIV-positive persons; on the contrary, this further increases their sensitivity and adds to their living under constant tension. In this context, medical specialists deepen the social exclusion of PLHIV by revealing their unprofessionalism:

I do what they tell me to do because I have suffered so much that I am tired of proving something to somebody. <...> [they] start saying: “and who is to blame?” You should not have a heap of diseases... because I have the whole bucket; I have hepatitis and HIV... And if you become sick with an older disease, if any of them reappear, then they like to say that if results or tests are bad, then they will certainly add that my disease (HIV) hampers treatment and will necessarily add that the disease does not respond to treatment because the virus is the problem... I think the opposite. <...> the tests do not show the same for everyone... [research participant (16) R]

The study participants state that life with HIV is complicated because they often do not receive good attention and understanding from medical specialists. For example, HIV written on test documents is a verdict in the true sense of this word – the silent rejection of the person when specific services are needed, for example to take samples for tests.

The obvious desire expressed by research participants to be loved with true love is not accidental. Some of the study participants cannot find their life partner due to individual reasons related to the feeling of true love, i.e. the need to love and be loved is significantly relevant. Some research participants indicated existing conflicts with family members, for example with their wives. After some time has passed since the HIV diagnosis, they initiate a divorce and tend to use blackmail saying they will spread information about the diagnosed HIV within their environment. The HIV-positive person experiences emotional shock and anxiety and tries to deal with the situation. Psychological help is often needed to manage conflict situations with wives; however psychological help is irregular. Thus, an HIV diagnosis is one of the preconditions for a person’s exclusion in a family expressed by divorce initiated by the partner.
A life with HIV is complicated. This can be illustrated by the following examples:

> it was in the detention institution, when they did not cut my hair. I felt... I don't know I went to the chief physician and asked why their barbers are not taught that it cannot be transmitted through the hair clipper. Although he told them that it cannot be transmitted, they still refused to cut my hair. I went... higher... to the mentor, and the mentor also told them to cut – but they did not cut my hair. I even went to the director. The director said that long hair is in fashion now. That was it... I wanted to write to higher institutions but I was detained just for a few days so I wouldn't have had time. The last one... but there were also more cases like that. Meanwhile, nobody helped me, and I left without having my hair cut.[research participant (6) F]

There were cases when I was in the rehabilitation centre and I was not allowed to communicate with girls. Only for me because I was the only one infected. [research participant (10) K]

In both cases there is an explicit attitude – to avoid, not to communicate, to refuse, etc. In this context, it becomes clear that there is a gap between the stating of scientific research results and the dissemination of this information in a language that would be understandable to the public and effective education of the public. The fact that the social exclusion of an HIV-positive person is encouraged in a rehabilitation centre by people who have information is surprising.

Experiences of PLHIV in their personal environment.

Realization of the person’s life situation determined by an HIV diagnosis. An HIV-positive person tries to “tame” his or her life situation, which is determined by the HIV diagnosis. A person’s realization of being diagnosed with HIV goes through two stages – emotional shock (concealment of the diagnosis from their close environment due to a fear of being rejected and a fear of talking, causing panic, depression, and constant deep stress) and psychological adaptation to their state of health determined by the diagnosis (there are two possible directions: the first direction, when a person examines more closely the meaning of the disease and its impact on his or her life, formulates new life plans, pays attention to the protection of his or her own health and the health of others, empowers himself or herself to inform their close environment about his/her HIV diagnosis, takes into account the needs of the environment and public attitudes, and realises his or her new needs; the second direction, where a person is not inclined to change his or her life and returns to a lifestyle that is detrimental to his or her health and that has determined their HIV diagnosis – the use of drugs – by setting a path for himself or herself for a fatal end).

Dual cognitive and emotional self-destruction or self-discrimination experienced by an HIV-positive person. An HIV-positive person contemplates the present and the future of his or her personal life after the establishment of the HIV diagnosis and reevaluates life values and feels “leprous” or “cursed” in society due to existing negative attitudes. The latter determine the HIV-positive person’s life, which is under constant tension, so that the remote environment and colleagues at work would not be informed by others, i.e. would not find out about their HIV diagnosis, because this would cause the creation of distance in their environment. Therefore, the HIV-positive person’s exclusivity in a negative sense lead to a double cognitive and emotional self-destruction, which could be called dual self-discrimination on a cognitive level and emotional level by imprisoning himself or herself in a world of his or her thoughts, perceptions and emotions and having no possibilities to openly share these things with others. In the context of this kind of self-destruction, a synergistic effect results – the public’s negative attitudes and the person’s awareness of them, as well as his or her fears and tensions cause a constant state of stress for the HIV-positive person which is experienced when the person tries to adapt to the environment and get used to their life situation that has been determined by the diagnosis. Therefore, the outcome is the maintenance of relationships with their
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

by concealing the HIV diagnosis and living in a constant and continued moral dilemma by experiencing the fatigue of living with the HIV diagnosis.

Public stereotypes and labelling. In a general sense public attitudes and reactions to PLHIV and HIV / AIDS issues are related to awareness and negative perceptions formed over time as a result of ignorance and non-awareness; therefore, PLHIV are identified with risk groups thus avoiding looking this disease in the following two ways: as a social problem and as a disease that must be treated and prevented. The lack of accurate and realised information about HIV in society causes stereotypical attitudes linked to the fears of members of society of becoming infected (the stereotype “HIV is like a plague”) and experiencing a quick and fatal end (the stereotype “HIV is a lethal disease”). Therefore, PLHIV experience psychological and emotional exclusion. Society has a characteristic attitude of “punishing” PLHIV by defiance and exclusion, not because of the disease but because of the behaviour that does not conform to the moral norms of society which has caused the person's infection with HIV in most cases. In this context, there is an imbalance between society's emotions and rationality – the HIV “shadow” often covers more complicated diseases such as hepatitis B or C, TBC with the ways of transmission being more efficient than in the case of HIV; however, the aforementioned diseases are stereotypically deemed by society to be the consequences of “poverty” or “an accident at work or in another environment”). Thus, the history of the origin of the disease in a general sense has an impact on societal stereotypes, which are difficult to overcome even when providing accurate and detailed information, because emotions often “push away” the accurate knowledge and result in inadequate and unprofessional behaviour even in professional communities which have accurate information and extensive knowledge of HIV. The non-awareness of the society has a direct impact on the humiliation of the dignity of PLHIV, which is determined by a fear of becoming infected.

Purification of relationships / interactions in the HIV-positive person’s personal environment. The HIV-positive person's openness to their close environment purifies the relationships / interactions between close family members and friends. “Falling out” between friends and relatives and the separation of partners due to their preconceived negative attitudes and stereotypes are frequent phenomena. This leads to the HIV-positive person’s realisation of their life situation determined by HIV diagnosis, and self-empowerment to assume responsibility for his or her quality of life. For this reason, there is a natural need for knowledge on HIV / AIDS in order to be able to manage his or her life and health condition and to empower himself or herself for independent learning by taking interest in social, psychological, and physiological issues as well as other issues related to HIV / AIDS. Education and learning as a manifestation of interest in one's disease creates preconditions for the HIV-positive person to understand and justify the existing attitudes in society as well as to learn to change them by empowering himself or herself with activeness, communication and self-introduction to others in a positive sense through one’s competence and emotional intelligence among other things. An HIV-positive person needs awareness and the will to inform his or her parents (family) who are often a source of moral and financial support for many of them. Having the moral support of family members, PLHIV often empower themselves to live a quality life and to fight for a full-fledged life.

Ignoring the riskiness of the HIV-positive person’s health situation determined by the diagnosis to himself/herself and the environment. Persons ignoring the complexity of the HIV diagnosis for their health do not empower themselves for change in life and the refusal of a harmful lifestyle. They are inclined to continue living in their usual environment of risky behaviour, which is dominated by withdrawal and ignoring strategies concerning HIV and the significance of this disease to themselves and the environment. In this case, PLHIV perceive their negative thinking, but they do not assume moral responsibility for the quality of their life and the protection of their own health and the health of others. PLHIV often inform their closest environment about the diagnosis of HIV but this is only a formality by “throwing off” the responsibility of potential consequences and the unchanged
lifestyle and the ways of HIV transmission determined by it become the responsibility not of the HIV-positive person, but of his or her environment that have an adequate lifestyle. The essential life concept maintained by PLHIV who project the responsibility for potential HIV transmission onto others is focused on understanding that life without HIV for a person addicted to drugs is a temporary thing; therefore, once one becomes infected, there is a reason “to go to the end”.

**Self-limitation of the competence of PLHIV to act.** Feeling the compassion and pity of their environment, PLHIV feel emotional discomfort because they understand the fears of the environment which are hidden by friendliness and other behavioural strategies. This kind of situation is perceived by an HIV-positive person not as support but as the non-recognition of the person’s equality and a gradual distancing from their ties with the external environment, because after the HIV diagnosis, the person’s activity load is reduced by a silent agreement that appeals to understanding and pity. This kind of situation leads to the gradual exclusion of the person both in their work environment and outside of it, i.e. in the formal social networks that are relevant to PLHIV in terms of activities. The potential outcome of this process is the (self)-limitation of the HIV-positive person’s competence to act in compliance with social behavioural norms and rules.

**Assumption of responsibility by PLHIV for their own health and the health of others.** When assuming responsibility for their own health and the health of their environment, PLHIV give themselves an opportunity to receive continual and systematic self-health care by giving up their detrimental lifestyle and bad habits that lead to the HIV diagnosis, by consciously taking medicines, eating nutritious food, and by distancing themselves from frequenting environments where alcohol or drugs are used, because intoxication may result in negative outcomes for their own health and the health of their environment. The implementation of the aforementioned factors by PLHIV demands great effort; work with themselves, consciousness, will, the realisation of one’s own health condition, and continual cultivation of knowledge concerning HIV / AIDS.

**Distancing themselves from knowledge concerning HIV / AIDS by considering it to be the problem of “others”.** Having stereotypical attitudes, society does not empower itself for changing them. Often an attitude remains that HIV is the problem of “others”, even though these “others” are the members of a society which all of us live in. Thus, the realization that takes place occurs at a slow pace and is linked to finding out new information about the number of new HIV cases from media sources or reading information about negative examples of PLHIV focusing on the context of risk groups. The process of slow and reality-ignoring realisation takes place in the environment of drug users as well, where a person informs their environment about the HIV diagnosis, but his or her companions, thinking only about receiving a dose, ignore the importance of the information and are interested only in receiving another dose. Drug users ignore the importance of changing syringes and might inject a dose with a syringe used by the HIV-positive person without recognising the danger to their own health and the health of their environment. A person addicted to drugs very often realises the situation only when he or she is diagnosed with HIV, and this has a particularly strong effect if the person has children for whom he or she feels responsible. Thus, the external stimulus to realize the significance of the HIV diagnosis for his or her own health and quality of life is their responsibility for their children or family; however, this does not mean that the person will stop using drugs. In many cases, they continue to use drugs, changing syringes and empowering themselves from time to time to communicate with a medical specialist or social worker (if they possess information about particular specialists who can help PLHIV).

**The HIV-positive person lives under constant tension.** Having realised the impact of the HIV diagnosis on his or her future life and health, the HIV-positive person, irrespective of his or her lifestyle, loses the joy of life, perceives the restrictions of his life, “imprisons” himself or herself in psychological and cognitive...
captivity by controlling their talk and behaviour in their environment and lives with their contemplation in “another” world. PLHIV tend to purposefully distance themselves from their external environment so that different interactions would not create any preconditions for their environment to ask questions, the answers to which would cause psychological tension for both PLHIV and the people surrounding them. Being aware of public attitudes, PLHIV place themselves in the limits of these public attitudes in order to adapt. The double psychological tension experienced by the HIV-positive person does not allow him or her feel comfort in life and causes depression, and for some – even a decision to choose a fatal end after the appearance of the accompanying health complications, in order not to become a burden for their family.

Individual experience of PLWHIV in the Educational Sector

What kind of problems do PLHIV face in the Lithuanian educational system? The majority of the study participants do not have direct negative experience regarding the situation of PLHIV in educational institutions; however, they presume that upon the disclosure of a person’s diagnosis, there might be special attention (not always positive) given to the HIV-positive student, which can create preconditions for social exclusion. The research participants presuppose that HIV-positive persons encounter problems in the educational system but they do not talk about them, openly fearing being condemned and because this can have “a negative effect on studies” (research participant (6) F).

The interview participants shared their experiences that there is a complex situation in the educational institution if you inform them about the HIV diagnosis – it is hard to keep confidentiality even though the person's documents contain a statement that it is forbidden to spread information about the person according to a specific law of the Republic of Lithuania. However a label is still put on them: it does not matter whether a person changes his or her life, tries hard, and attends the programmes; their environment still views him or her not as a person but as a “label”, for example, a drug addict. This is an obvious manifestation of social exclusion. The study participants indicate that HIV-positive parents who have children do not inform educational institutions about their disease so that there are no problems for their children. Thus, the strategy is clear: “if you don’t say anything, then you won’t have problems”.

How could education specialists help PLHIV? In educational institutions, there is a demand for specialised medics, and even for rooms where PLHIV could come for information: PLHIV have various questions regarding vitamins, food supplements, consumption of foodstuffs, etc. There is a lot of information on the Internet, but PLHIV need face-to-face contact with an expert.

Teachers also must be provided with more information about the health condition of HIV-positive persons, such as the negative side-effects they experience while taking specific antiretroviral medicines. This kind of knowledge enables teachers to change their attitudes and educational methods – HIV-positive persons have difficulties in remembering large amounts of information, they get tired faster, etc. The study participants believe that HIV-positive persons do not need special attention or conditions in educational institutions because this would encourage social exclusion: it would stimulate the negative opinion and negative attitudes of the educational community and thus enhance the emotional and psychological discomfort of the diseased person.

The research participants state that it is necessary to provide students with information about assistance to PLHIV and the ways of HIV transmission in schools. This is a precondition in order to not to be afraid of HIV-positive persons, not to promote their social exclusion and not to live in psychological discomfort when they encounter HIV-positive persons. The personnel in educational institutions respond controversially not only to HIV but also to other diseases, i.e. they have preconceived attitudes and fears. Some participants claim that people may avoid extending their
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<td>Need for a specialist or specialised room for HIV-related issues in educational institutions</td>
<td>Need to contact the specialist regarding information on the use of vitamins</td>
<td>There must be special rooms or special physicians who you could come to. So that one knows what to use, for example, I don't know now what vitamins I can take and what vitamins I can't take.</td>
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<td>Need for a psychologist or psychotherapist in school regarding information on the consequences of HIV on the quality of learning</td>
<td>There could be a psychologist, a psychotherapist, who would know more about the consequences of HIV on the memory and abilities of such people and would give lectures to teachers... &lt;...&gt; however, the requirements must be the same, just if one says 'it is hard for me to memorize', maybe the teacher could take this into account, and in order for him to take this into account, he must have information that this could happen.</td>
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<td>Need to be understood in the educational institution due to HIV-related health changes</td>
<td>Need for a smaller workload and multiple explanations by the teacher due to increased fatigue and weaker memory</td>
<td>Teachers should take into account and somehow explain everything several times to that person, or well not to demand to learn everything in one lesson &lt;...&gt; Of course, they must take this into account by all means because this “hits your brain”, I, for example, know this based myself. I don't have memory, so I forget. So, they must take this into account.</td>
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<td>Creation of exceptional conditions for HIV-positive persons – a precondition for encouraging exclusion in educational institutions</td>
<td>Creation of special conditions for HIV-positive persons in educational institutions – encouragement of negative attention of the environment</td>
<td>No, I think that no special conditions are needed. Just to learn with others as everybody does. I don't think that any sexual intercourse will take place or they will inject there during the lessons... but to exclude people, then you will simply draw the attention of all the others to them,</td>
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<td>Creation of special conditions for PLHIV in educational institutions – increasing of emotional and psychological discomfort of infected persons</td>
<td>&lt;...&gt; I cannot imagine that, exclusivity is exactly what is not needed, so that they would treat you as a person, as an exceptional person &lt;...&gt;</td>
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<td>Need for schools to assume responsibility for the provision of objective information about HIV to students</td>
<td>Information about possible solutions to the problem of HIV infection</td>
<td>Maybe they should talk about it in schools... I think the school should talk about this... not in an intimidating way but that it is like this and like that, that it is unavoidable, there is such a problem that can be resolved...</td>
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<td>Information about the life of PLHIV after the diagnosis</td>
<td>&lt;...&gt; one can live with it &lt;...&gt;</td>
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<td>Teaching people not to be afraid of those who have been diagnosed with HIV</td>
<td>&lt;...&gt; that there are such people who should not be feared...</td>
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<td>Information about help for PLHIV</td>
<td>&lt;...&gt; so that they know what places are harmed by this disease,</td>
</tr>
<tr>
<td></td>
<td>Information about the effect of HIV on the human body</td>
<td>They must talk about this on a wider scale. A person will not come... being sick with HIV, while sitting at one desk with a healthy person, will not transmit HIV to him or her. They must educate people about this, so that they are not afraid of this disease. They will not come and stab you with a syringe,</td>
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<tr>
<td></td>
<td>Information about HIV prevention</td>
<td>&lt;...&gt; so that they perceive how to go around and present information so that one would truly understand it.</td>
</tr>
<tr>
<td>Negative attitudes of educational institutions towards PLHIV</td>
<td>Connection between the attitude of employees of educational institution and the diagnosed disease</td>
<td>&lt;...&gt; I cannot imagine what the reaction of employees or educational institutions would be if they found out that some student has HIV or AIDS, or anything else. You can have tuberculosis here – and there will be a totally different attitude towards you.</td>
</tr>
<tr>
<td></td>
<td>Fears in the environment of educational institutions regarding any chronic disease</td>
<td>People simply &lt;...&gt; another person who has any disease... it might be even cancer – and then they will already be afraid of extending their hand to greet them &lt;...&gt;</td>
</tr>
<tr>
<td></td>
<td>Distancing of the personnel of educational institutions from the reality of life in the context of various diseases</td>
<td>&lt;...&gt; people do not understand all these diseases, they are very distant and all of them think that somebody is ill somewhere but not me.</td>
</tr>
<tr>
<td>Need to educate children by developing their social competence</td>
<td>Provision of information on HIV early on in childhood</td>
<td>Most probably more information about this must be disseminated. While a child is still small, And society must educate such children so that they are not afraid of such children, simply be together with them.</td>
</tr>
</tbody>
</table>
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

Deepening of knowledge and information about HIV by parents whose children learn in schools

| Provision of information on HIV to parents based on scientifically proven arguments |
| First of all, this kind of information should be provided to parents, teachers or similar persons, to those for whom it is important to know, and to explain that this is not horrible. How it can be transmitted, etc. |

Deepening of knowledge and information on HIV by teachers

| Provision of information to teachers about HIV transmission and the ways of transmission based on scientifically proven arguments |
| <...> for teachers <...> it is important to know, and to explain that this is not horrible. How it can be transmitted, etc. |

| Provision of information to teachers about the effect of HIV on the body and consequences related to the quality of learning based on scientifically proven arguments |
| Depending on the extent of the infection. As we are aware, HIV infection… it… its main reservoir where HIV infection cannot be reached even by medicines is the brain. The spinal cord and the brain. Even if medicines totally destroy HIV in the body, it remains in the brain. And therefore the phenomenon <...> is frequent that sometimes PLHIV suffer from mental disorders, they become nervous. It is harder for them to memorize something. <...> there are such cases. <...> in this case, teachers should have more information. |

Need for professional education for educational specialists

| I have children and this is <...> the problem is not infected people in the educational institution but their children. <...> if one of the children finds out that another child’s father is infected or mother, or parents? What might be the consequences? <...> rumours, children are laughing, taunting <...> in this case, what could educational institutions do? There should be education in school. But in order to have proper education, a teacher must be trained or there must be specialists in an educational institution, who could organise sessions, supervisions to other form tutors or teachers <...> how to behave in a certain situation. You can never know when this information ‘will come out.’ Today there are no children, but maybe tomorrow... |

What would facilitate the integration of PLHIV in the educational system? The study participants claim that the attention of teachers is very important for HIV-positive children but not attention that is preferential and based on labels. This means that there is a need in school for equal treatment in order to maintain the dignity of the children and their self-esteem.

The research participants state that special treatment is not needed in the learning environment; however, an individualised attitude towards the learning needs of PLHIV is required, for example, repeated explanations, division of the load into parts so that the person could memorize and understand it better and would feel satisfaction in the learning process. Thus, true concern is expressed towards the HIV-positive person’s health1. The respondents spoke about the self-empowerment of educatio-

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1 For a more detailed description of the changes in the health of HIV-positive persons please see the Section about the situation of PLHIV in the health care system.
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

The persons who participated in the interview claim that all personnel of educational institutions need training on HIV. This means that they must develop their competence in health care and disease prevention.

The study participants state that education of students must be targeted:

“They could explain the situation to students or children that this is not bad, and this person is not dangerous to others. Not only to them, but also to students’ parents, because they are mostly concerned with this. There are more dangerous diseases, and adolescents using drugs very often have hepatitis – B or C. <...> not talking about all the other diseases that are being spread. And what about all the other sexually transmitted diseases – syphilis, gonorrhoea...“ [research participants (4) D, (10) K, (20) V]

The study participants believe that the integration of PLHIV and their children in educational institutions directly depends on the dissemination of knowledge and obtaining of accurate and scientifically proven information:

There should be some consultation on the subject. There should be communication and discussion on the subject. Because, for example, when I found out about my HIV status, right? After I had just learned about it...at least to talk on the subject, nobody knew where to refer me, where I need to go.... Cars go, people pass... and I left and did not know where I should go now... And I think in kindergarten, in school, when people would find out that the child’s parents are infected, they would be shocked as

<table>
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<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Interview statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equal communication with all students without labelling</td>
<td>Need for dignified and respectful behaviour with HIV-positive students</td>
<td>To behave with them as with students rather than patients, to not exclude them.</td>
</tr>
<tr>
<td>Need to implement the principle of respect for personal dignity in schools</td>
<td>Implementation of the principle of equality in work with students in educational institutions</td>
<td>&lt;...&gt; here it is most difficult to describe because I think that there is no difference whether somebody is ill or not ill, or infected or not infected person, it does not matter at all.</td>
</tr>
<tr>
<td></td>
<td>Maintenance of confidentiality in respect to PLHIV</td>
<td>The most important thing is confidentiality, which is greatly missed not only among teachers but also among medical specialists, etc. In all instances.</td>
</tr>
<tr>
<td>Demand for competent psychological support</td>
<td>Psychological preparation of individuals to accept HIV diagnosis</td>
<td>In this case, maybe more psychologists. It happens that people go even all the way to suicide. Well, for example, my friend could have committed suicide, he even tried to hang himself. Again, I am saying a person has to be prepared for this.</td>
</tr>
<tr>
<td>Concern about the health of the HIV-positive student</td>
<td>Individual attitude towards the learning needs of HIV-positive persons</td>
<td>&lt;...&gt; to take into consideration that maybe there will be a need to explain it more to him or repeat the same thing more times...</td>
</tr>
<tr>
<td></td>
<td>Greater attention to the maintenance of the HIV-positive person’s health</td>
<td>For an infected person, maybe it would be more difficult to study because of his or her health, so maybe it would be possible to take this into account.</td>
</tr>
<tr>
<td>Need for the personnel of educational institutions to develop their competence in the field of disease prevention</td>
<td>Need for training on HIV for the personnel of educational institutions</td>
<td>There should be very serious training/courses for them, so that they understand what this is and that every person has it and walks around all his life, maybe even teachers themselves carry other viruses which are no better than that HIV virus and the further we go, the more and more of these viruses are identified in medicine. And very soon, I think, in a couple of years, it will not be surprising that you have a virus of some sort because there are hundreds and hundreds of types of these viruses...</td>
</tr>
<tr>
<td></td>
<td>Need for education of students</td>
<td>I would think that more information should be provided to them. Because the lack of information among teachers is huge. Most often they do not even think about this. Particularly, in rural areas there is a “dark forest”, nobody knows anything. In cities, maybe a little more. There is also that sexual education, as far as I know. Maybe they know a little more there.</td>
</tr>
</tbody>
</table>

Table 6. Factors Creating Possibilities for HIV-Positive Persons to Integrate in the Educational and Training System
The above extract from an interview reveals that PLHIV admit that having found out about the person’s HIV diagnosis, the environment experiences shock much like the HIV-positive person himself/herself experiences; therefore, the school’s community must be prepared not when it occurs but systematically. According to the study participants, the professional help of a psychologist is important: a person diagnosed with HIV must be prepared to accept this diagnosis soberly and to assess the situation rationally by empowering himself or herself to assume responsibility for the quality of their own life.

Experiences of PLHIV in the educational system.

Fears of the HIV-positive person. PLHIV experience the fear of being rejected after informing others about his or her HIV diagnosis because they do not trust the ability of their environment to keep confidentiality and are afraid of negative attitudes which manifest themselves as special attention towards PLHIV, and not always in a positive sense. Therefore, PLHIV make a decision to inform their environment only in exceptional cases according to the need and intensity of communication with particular persons. However, opening up poses a great risk of being excluded and rejected emotionally and socially; therefore, the main motto “if you don’t say anything, you won’t have a problem” remains.

Demand for specialist assistance provided to PLHIV in the educational system. Communication with a medical specialist and a psychologist according to need is vital for PLHIV. The medical specialist in the educational system should not only perform the role of a consultant but also engage in educational activity by working with the school’s teachers because the latter forms attitudes in the school. Informed teachers would not create preconditions for stereotypes to become entrenched and would take into account the learning possibilities of HIV-positive students according to their health status. Strong fatigue, and difficult and short-term concentration of attention due to medical treatment cause complications in the learning process, i.e. it is harder for HIV-positive persons to memorize something, they need a more frequent repetition of the task, and multiple explanations of subjects. By being aware of the specific aspects of work with PLHIV in the classroom, teachers would create preconditions for the formation of an atmosphere based on tolerance and goodwill in a class, in school, i.e. in an educational institution. However, neither special learning conditions should be created nor specific attention should be paid to PLHIV because the “special treatment” strategy would cause social exclusion for PLHIV in educational institutions. A psychologist should think about the strategies of work with PLHIV in learning environments because PLHIV are dissatisfied with the current strategy applied by psychologists’ communication / contacting / consulting PLHIV due to the stereotypical phrases, addressing and questions that are used which do not encourage PLHIV to open up.

Need for schools to assume responsibility for the provision of objective information about HIV to students. Due to the lack of information, teachers working in the educational system are categorical and adhere to stereotypes not only in interacting with PLHIV but also with people with any contagious or chronic disease. Ignorance triggers psychological tension and poor reactions projected on to people living with this disease or their close family members. The imbalance between emotions and rational thinking impacts the entrenchment of categorical attitudes and a culture of stereotypes in educational and training institutions. The analysis of the experiences of PLHIV revealed the necessity to develop social competence of students in schools, to promote their awareness of general life values, to involve parents in the awareness-raising process by providing information about HIV / AIDS based on scientific arguments, and to develop and expand specific knowledge (of anatomy, physiology, infectology, pharmacology, psychology, educology, sociology) of teachers related to the HIV / AIDS context. However, education must
be professional, carried out by professional medical specialists and psychologists who have experience in working with PLHIV. Also relevant is the engagement of PLHIV themselves in education within educational institutions by transferring their experience to school communities. The purpose of a psychologist in the educational institution would be to prepare the environment to accept an HIV-positive person as a human being rather than as a diagnosis. Thus, cooperation between different specialists and PLHIV and communities of educational institutions would provide conditions for the creation of the environment based on tolerance, goodwill and maintenance of personal dignity in educational and training institutions.

Factors creating preconditions for PLHIV to integrate in the educational and training system. In schools and in all educational and training institutions in general, there is a need for moral transcendence from defiance, distancing, disassociation, fear and tension caused by ignorance, insecurity and distrust, being categorical, secrecy, condemnation, non-awareness, diagnosis-related stereotypization and lack of knowledge, but an attitude that is directed towards maintenance of personal dignity, goodwill, tolerance, equality, maintenance of confidentiality, self-empowerment to expand one’s knowledge and deepen accurate knowledge, dissemination of information, and recognition of an individual as the highest value. The existing absence of necessary human, material and professional information resources,

Table 7. Employment Possibilities of PLHIV in the Lithuanian Labour Market

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<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Interview statement</th>
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Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

Preconditions of PLHIV regarding the possibilities of integration in the labour market

- Decision to not speak about the diagnosed HIV to the employer due to a fear of being rejected
  - I don’t even know how it should be done. Most probably, it should be done. If there are really no other possibilities and you really need a job, then most probably to not say that you are infected. Well, it also depends on the employer...but I have not heard of cases like that.

- Conscious decision not to contact employers regarding employment because of the diagnosed HIV
  - When I had a job, I did not say that I... that I am infected with HIV... I am a cook according to my qualifications... I know exactly that I will not be able to get a job anywhere according to my specialty. This, of course, causes me problems – I have qualifications but I cannot get a job anywhere with them...

Conscious concealment by PLHIV of their health status from employers

- No informing of the employer – no problems at work
  - Well, I don’t really know. Whether the employer, whether he knows that you have this HIV, or only that. Because if the employer doesn’t have that kind of information about you, I think there are no problems. And what does that change then? If they let you work in the food industry with this virus, then this is not an exceptional matter.

- Disclosure of HIV diagnosis to the employer – a precondition to lose a job
  - It can be said that this is a very difficult thing. Having come to look for a job and said that I have HIV – it is practically impossible to get the job. I think there are no other possibilities and you really need a job, then most probably to not say that you are infected. Well, it also depends on the employer...but I have not heard of cases like that.

- One has to be dishonest in order to get a job
  - I think that maybe I would purchase a certificate that I am healthy. I don’t really know. Whether the employer, whether he knows that you have this HIV, or only that. Because if the employer doesn’t have that kind of information about you, I think there are no problems. And what does that change then? If they let you work in the food industry with this virus, then this is not an exceptional matter.

The HIV-positive person’s fear of making the information about his or her disease public

- Use of drugs by employees is considered by the employer to be a bigger problem than HIV
  - With discrimination. There are more aspects, including health-related ones. Not all people can do physical work. I will repeat myself again, you cannot compare all people with HIV according to some sort of rater. One can (do) physical work, another may be 50 kg can carry on his back for another 5 years and everything will be OK for him. For someone else... So, again, one has to look at their health condition, unfortunately, a person cannot say this, and cannot say this in the labour exchange either. And the main reason for this is discrimination. Everything is related to this, that a person cannot say anything about his health because he or she is afraid to not be accepted <...> A vicious circle.

- Inadequate attitudes of the employer regarding employees’ bad habits determined by societal stereotypes
  - Because I have worked, I have encountered this. I have worked over two months and they found out, well, but there was more there, that I use drugs. He started to see things, that I am stealing. And it was not important for me to steal, why I should steal when I receive money every week, I earn it. It was very good for me, I could support myself and not ask my mother.
problems related to work. In the opinion of the research participants, one of the possibilities to get a job is to purchase a health certificate stating that a person is healthy, i.e. to be dishonest. The study participants claim that the non-awareness of employers creates preconditions for the social exclusion of PLHIV: having no accurate information and not knowing the subtleties of the disease, employers consciously avoid hiring PLHIV, irrespective of their professionalism and competence. It is not the human being, or personality, that takes first place but his or her disease, or health status. For this reason, it is practically impossible to be successful in receiving a job by openly disclosing information about the diagnosed HIV. Thus, it may be presumed that negative attitudes and the lack of information create conditions for employers’ decisions that are unfavourable concerning PLHIV. The main restriction in the employment of PLHIV – the concealed information about the diagnosed disease – is the manifestation of the fear of being discriminated against concerning employment. This means that it is safer for an individual to withhold from speaking about his or her HIV infection when looking for work even though this is unfair and immoral to society.

What would PLHIV need from employers so that they could adapt at work and make employment more accessible? The research participants claim that as HIV-positive persons have various experiences, for example, imprisonment or drug use, it is very difficult to find a job. Therefore, they have to look for other ways, such as learning, or acquiring qualifications. However, even those PLHIV who have qualification certificates cannot find a job, and the labour exchange does not offer anything to them either. It is not preferential treatment that is important but equality for HIV-positive persons in the labour market. This means that human dignity is also important for PLHIV in the context of the labour market. One of the study participants whose works in the service sector states that he has had no problems at work because nobody is informed about his diagnosed HIV; however, the person claims that in talking about access to employment for PLHIV, they need a reduced workload due to faster fatigue.

PLHIV state that specific laws creating preconditions for HIV-positive people to have their rights and guarantees and encouraging employers to employ PLHIV are needed. The excessive display of compassion is annoying and causes tension for an HIV-positive person and simultaneously prompts social exclusion: a person is not allowed to carry out certain activities which he or she is capable of carrying out, and the arguments are based on the person’s health status because of their diagnosed HIV ("It is hard for you" [research participant (18) T]).

The interview participants state that employers need training on HIV – this would create preconditions for the enhancement of their tolerance and development of their understanding, and at the same time would be prevention of social exclusion in the context of the labour market. Accurate and detailed information provided to employers would create preconditions to be more tolerant and open, and there would not be preconceived negative attitudes towards employing PLHIV. Being aware that a person is infected, the employer and his environment are safe, while the concealment of the HIV diagnosis leads to a simulated situation that “everything is fine”, whereas in reality this kind of situation is unsafe:

<...> would employ knowing that a person is infected. So that they would understand that this HIV will not be transmitted while working. Even if a person has injured himself or herself <...> it is better for the employer, that he knows that the person is infected. He is already protected by having this information. Let us say, I come to work and I don’t say that I am infected with HIV, when in fact I am. The employer feels calm, he does not know that I am infected. I injure myself, and here he should feel anxiety that he does not know. And if he employs me and knows, he would be calm that if I get injured, he knows what to do. <...> people do not understand that not knowing is horrible, and knowing is power. This discrimination gives rise to ignorance, and this poses an even greater threat than himself or herself [the one who has HIV] ...[respondent (20) V]

Are Lithuanian employers ready to adapt to the needs of PLHIV? The research participants are certain that employers are not ready to take into consideration
the needs of HIV-positive employees. Employers are a cell of society, a part of society which lacks information and knowledge, which is why they are influenced by common negative attitudes and stereotypes concerning PLHIV. Thus, education is the primary activity that would create the founding preconditions for employers to distance themselves from traditional negative stereotypes.

Experiences of PLHIV in the labour market.

**Employment possibilities of PLHIV in the Lithuanian labour market.** The most frequent decision of an employed HIV-positive person is to not inform their employer and their work environment about his or her HIV diagnosis because it would result in the loss of their job and social exclusion, and financial sources are important resources to receive treatment, eat nutritious food, and to fulfil financial obligations for one's family. When PLHIV are employed, they are not inclined to disclose their diagnosis to their employer because if there is an alternative to choose between two employees, the “healthy” one will be chosen, despite his or her other habits, even if they are harmful. One of the illegal and, one could say, immoral solutions as viewed by PLHIV is to acquire a health certificate stating that they are healthy. The latter statement was mentioned by PLHIV only as a consideration of the possibility, even though none of the research participants had such an experience. The major obstacle in the labour market is the non-awareness and ignorance of the need for knowledge about HIV/AIDS of employers themselves, which leads to a stereotypical approach and negative attitudes concerning PLHIV: they see the HIV diagnosis rather than a person's professional qualifications, competence, and capacities based on work experience. Therefore, equal competition for a job with other persons who are not infected with HIV but may have different habits and other diseases which can cause problems in the work environment is practically impossible for PLHIV. For this reason, PLHIV consciously do not inform their employer of their health status, realising their moral and social responsibility for such a decision, and giving themselves the power to protect their own health and the health of others.

**Needs of PLHIV to adapt in the labour market.** In the labour market, it is not a special status but equality, i.e. human dignity in the labour market context, which is important for HIV-positive people. Specific laws creating preconditions for HIV-positive people to exercise their rights and guarantees and that are also encouraging employers to hire PLHIV are necessary. Employers must have training on HIV which would enable the development of their tolerance and understanding as a means of preventing social exclusion in the context of the labour market. The concealment of an HIV diagnosis only poses problems to an HIV-positive person relatively (“as long as they do not know, there are no problems”); however, this is an artificial situation, the social consequences of which may be revealed at any time – the HIV-positive person's decision not to inform their environment is a defensive position determined by societal stereotypes and attitudes, which are also held by employers, while the non-awareness of HIV among employers and ignoring of the need for this information in all work environments is irrational because ignorance in the health statuses of employed persons is a precondition for an unsafe work environment, and knowing is power and the ability to ensure safety by general humane, social and morally acceptable solutions, while ignoring the stereotypes that have already become standardised concerning PLHIV and maintaining the dignity of an HIV-positive person and that organisation.
Table 8. Health Disorders of PLHIV

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<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Interview statement</th>
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<tbody>
<tr>
<td>Negative consequences for physical health</td>
<td>Excessive sweating at night</td>
<td>&lt;...&gt; the main thing is that I sweat a lot, all the time I get up wet at night.</td>
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<tr>
<td>Weakness</td>
<td>And weakness</td>
<td>&lt;...&gt; constant weakness...</td>
</tr>
<tr>
<td>Fatigue</td>
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<tr>
<td>Quick exhaustion</td>
<td></td>
<td>You become exhausted very quickly.</td>
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<tr>
<td>Loss of appetite</td>
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<tr>
<td>Vesicular skin rashes</td>
<td>Herpes, maybe that’s why I have more rashes.</td>
<td></td>
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<tr>
<td>Constant feeling of heat</td>
<td>I am hot</td>
<td>&lt;...&gt;</td>
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<tr>
<td>Morning weakness</td>
<td>It’s not good, no strength. A person gets up in the morning full of energy, there's something somewhere... I am not like this, I get up and think – here we go, I need to &quot;live through” one more day somehow, to suffer one more day, well, so, I'm awake...</td>
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<tr>
<td>Leg pain</td>
<td>And now I have problems with my leg, before I had problems with my spine. The surgeon who performed the operation on my back said that you have a very weak immune system. But he said this in hints but he did not say anything directly and did not make any tests, they don't make tests. ... now my leg has some kind of thrombophlebit...</td>
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<tr>
<td>Long-term depression condition</td>
<td>such depression, it’s not going away, it’s lasted for six months...</td>
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<tr>
<td>Frequent colds</td>
<td>Most often, there are all kinds of cold infections. Well, you go somewhere by bus, somebody sneezes – you catch a virus. You use antiretroviral medicines but still this infection gets into the organism.</td>
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<tr>
<td>Digestive system problems</td>
<td>There are problems with the digestive system...</td>
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<tr>
<td>Liver disorders</td>
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<tr>
<td>Seborrhea</td>
<td>Diseases... seborrhea. First, I thought that those are problems with my skin but later I found out that this can be related to a weak immune system.</td>
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<tr>
<td>Excretion system problems</td>
<td>&lt;...&gt; kidney disorders...</td>
<td></td>
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<tr>
<td>Enlarged lymphatic nodes</td>
<td>Enlarged lymphatic nodes.</td>
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<tr>
<td>Good health status at the beginning of HIV infection and treatment against it</td>
<td>Absence of health complications caused by HIV</td>
<td>&lt;...&gt; at the moment, what is caused by HIV, I couldn’t say.</td>
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<tr>
<td>Low morbidity</td>
<td>But my own morbidity is low.</td>
<td></td>
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<tr>
<td>Rare morbidity</td>
<td>One time per year practically.</td>
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</tr>
<tr>
<td>Complexity of distinguishing between their HIV-related condition and their general condition</td>
<td>Failure to distinguish the symptoms characteristic of HIV</td>
<td>It is hard to say now in the recovery stage, all those signals sent from the inside, they are mixed with the general condition that it is impossible to say what is associated with that virus and what is associated with the recovery.</td>
</tr>
</tbody>
</table>
Impact of secondary diseases suffered before HIV diagnosis on the current health status

| Impact of secondary diseases suffered before HIV diagnosis on the current health status | I have one problem with HIV, this is that secondary... Because I had a fever in some part of the brain and I can still feel its consequences. Practically I was hospitalised not because of HIV but because of that thing. |
| Motivation to empower oneself for a quality life with HIV | There must be good nutrition, so that HIV would not chew you up, you must feed it. To keep the organism in such a state that “the wolf would be full and the sheep healthy”. Nutrition, vitamins, sleep are important everywhere. This is the case where you have to combine everything, there must be a regime. But there are not always conditions for this. And sometimes it seems that I read, I have information know a lot, compared to other people who have HIV, and try to do this, I want this. |

**Personal experience of PLWHIV in Health Care Sector**

**What kind of health disorders do you have that have been caused by HIV?** A study participant who had been diagnosed with HIV only a few days ago does not have any experience with bad health, i.e. the negative effects caused by HIV or medicines. Their chance of falling ill had been moderate before the HIV diagnosis. Some respondents state that it is difficult to distinguish between the symptoms related to HIV and those that are not related to this infection during the initial stage of the disease. However, the majority of the interviewees claim that life with HIV is complicated due to physical senses, for example, constant sweating which is excessive at night, fever, weakness, quick fatigue, spine and limb pains (many are diagnosed with thrombophlebit), long-term states of depression, and vesicular skin rashes and mucous membrane irritations. The “relationship” towards food changes: they do not have an appetite, eating turns simply into a “duty”, no satisfaction is felt while eating even though the taste of the food is felt just fine.

The description of one’s health status is also influenced by the information on the test results: when information is detailed, they have a lot of information, then the description is related precisely to the tests. For example, one of the study participants claims that blood test results revealed that he has “a very small amount of cells”, that he considered himself to be “a live corpse” because “he was going around without cells”. These kinds of descriptions are full of metaphors and allegories and they reveal that PLHIV are very sensitive towards medical information about their health status. Some interviewees’ link their current health status with the diseases suffered before their HIV diagnosis, for example, brain fever suffered in the past is to blame for their poor physical condition, headaches, or vertigo.

**Where do you receive the required medical assistance and advice? What kind of physicians do you visit?** The study participants perceive the need to maintain their health; however, the main barrier in contacting specialists is financial. For example, an odontologist provides paid services, which a study participant needs but is unable to find accurate information about financial assistance. This shows a situation that the HIV-positive person himself or herself creates myths and avoids asking for accurate information because *on one hand* it raises anxiety; while *on the other hand*, there is no efficiently functioning system for the provision of accurate information with regard to the variety of cases that are relevant to them.

The majority of interview participants are conscious and open with medical specialists: when contacting medical specialists for help, they inform medical specialists about their diagnosis or plan to do so because they perceive that openness and cooperation create more possibilities of remaining employable and valuable within the context of maintaining one’s health. Some study participants state that they deal with the problems that arise on their own and they do not need any medical specialists yet, or their friends become intermediaries by passing on information or encouraging them to visit at least a family physician.
Some research participants state that they do not contact physicians after their HIV diagnosis because they don’t know where to go – this is related to their conscious choice not to communicate with or have contact with their environment. They are not afraid to contact medical specialists or other needed specialists but they have a clear attitude that they would not listen to them unconditionally, and that they will adapt only part of the information provided by a medical specialist according to his or her own needs. For some research participants, only visiting specific specialists is relevant, for example, an infectologist, gynaecologist, proctologist, etc. The overall morbidity with other diseases is rare in the case of many research participants.

The study participants are very happy if they come across excellent medical specialists that are excellent not only as specialists but first of all as human beings. The essential assessment criterion applied to medical specialists by HIV-positive persons is professional ethics expressed by the ability of maintaining secrecy (confidentiality) concerning the patient’s information. The study data allow stating that contact with their family doctor, infectologist and odontologists is most relevant for HIV-positive persons.

Have you ever been treated differently by medical specialists because you are infected with HIV? Some study participants stated that the behaviour of medical specialists with them is not discriminatory. In particular, it is helpful when a medical specialist knows information about the patient infected with HIV so additional questions, which may even embarrass an HIV-positive person are not asked. The respectful and unbiased behaviour of health care specialists is important for PLHIV.

There were negative, unethical cases related with the behaviour of the following medical specialists:

- nurses

  The nurse hands a syringe to an HIV-positive person and instructs the person to stab it into the vein and extract blood by himself, and provides unprofessional arguments that she cannot find it, though an HIV-positive person knows that blood is taken from other people by nurses themselves.

- physicians

  Without obtaining a permit from an HIV-positive person, the family doctor informed his mother and provided only negative information on HIV, thus creating preconditions for social exclusion in the family. The mother has been afraid to touch her son for several years.

  The study participant had to carry a baby and to give birth after becoming infected with HIV. She has experienced psychological pressure and rude behaviour from medical specialists, which is an expression of the humiliation of personal dignity.

  The research participant experienced the stereotypical labelling as a drug addict by a physician: having arrived to the surgeon at the outpatient’s clinic after postsurgical inpatient treatment and having informed him that he is infected with HIV, the physician did not read the documents and stated that the person is a drug addict and the mark on his leg means that drugs were injected into his leg. It was a great emotional shock for the research participant to hear such a statement from the physician’s mouth because the HIV-positive person has not been and is not addicted to drugs. So, physicians show their unprofessionalism as a result of being influenced by the preconceived stereotypical negative attitudes based on the labels put on people without going deeper into each individual case:

  I had surgery on my leg when it was broken. I went to the doctor at the outpatient clinic, showed him my leg, and told that I have HIV. I didn't even have a chance to start to explain the problem... And I put a paper on the table, a hospital record certifying that there had been an operation on… due to a fracture, etc.

  Without even reading his paper, he established the diagnosis – trophic ulcer, and that I am a drug addict. It was a shock to me... A person has immediately concluded...
Table 9. Behaviour of Medical Specialists towards PLHIV

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<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Interview statement</th>
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<tbody>
<tr>
<td><strong>Professional behaviour of medical specialists towards HIV-positive persons</strong></td>
<td>Adequate behaviour of the informed physician with the patient</td>
<td>No, I don’t go to them. I went to one and I was[there] regarding the issue of hepatitis. He knew everything and there was nothing special.</td>
</tr>
<tr>
<td></td>
<td>Integrity of the physician’s understanding and empathy when communicating with HIV-positive persons</td>
<td>I haven’t noticed. Most probably, it’s like it was, if I haven’t noticed anything.</td>
</tr>
<tr>
<td><strong>Behaviour of medical specialists that maintains the dignity of PLHIV</strong></td>
<td>Social intelligence of the specialist who has diagnosed HIV while communicating with the patient</td>
<td>I usually go to my family physician who is a great doctor and always understands. This was the first medical specialist, except for the employees of the AIDS Centre, who learned about my condition. She understood me immediately and looked at it very well.</td>
</tr>
<tr>
<td><strong>Behaviour of medical specialists that humiliates the dignity of PLHIV</strong></td>
<td>Refusal by nurses to take blood from an HIV-positive person by giving unprofessional arguments</td>
<td>There have been no such cases yet. The only person is the head of the laboratory who told me that it was positive. But she acted in a normal way, in a pleasant way.</td>
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<td></td>
<td>Silent request of medical specialists for an HIV-positive person to “serve himself” when bandaging the wounds</td>
<td>Treated... When I come to give CD4 blood, they simply give me a syringe and tell to extract blood by myself. &lt;...&gt; They say they cannot find the vein... These are the specialists who have to get blood, the nurses. &lt;...&gt; Yes, they don’t get blood. They get blood from the entire hospital but they cannot get my blood.</td>
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<td></td>
<td>Need for a behaviour other than “at a distance”</td>
<td>There was. I was hospitalised in the isolation hospital for my legs. There were a lot of damp wounds, so I had to do this myself... They would come and look, but I was bandaging myself. They come, take, look and bandage up. And that’s it. I could feel that right away. At a distance.</td>
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<td></td>
<td>Rude behaviour of the physician concerning an HIV-positive woman during the childbirth</td>
<td>For example, a person has cancer – they go, nurse you and look after you. And how are we different? No difference. Understanding... so that they could communicate, treat one in a humane way, and would not categorize – this person is like this and that person is like that.</td>
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<td></td>
<td>Scepticism experienced from medical specialists</td>
<td>It was during childbirth here, they started to shout at me that ... Well, they started to speak in a raised voice... that how could I not look after myself and that I was using drugs while pregnant... I explained that I could not stop using them because they did not let me in the AIDS Centre. They just instructed me to reduce the dose so that the child would not have convulsions once born... Because I wanted to stop using, but they did not let me... How can one do that... They started to shout because of the operation room, that the operation room would have to be disinfected now... We have not had similar cases before... they treated me in a very rude way...</td>
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<td></td>
<td>Unethical behaviour of the physician regarding the disclosure of information to the HIV-positive person’s mother</td>
<td>In the AIDS Centre, - no, of course not. But in other institutions - yes. From a person’s way of talking – like you are the one that has collected diseases for yourself... from a person’s behaviour... they open the clinical records, and there it says HIV, and they look at you with such irony like what did we do here...</td>
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<tr>
<td><strong>Violated principle of the ethics of confidentiality</strong></td>
<td>Conscious negative attitudes of PLHIV concerning medical specialists</td>
<td>&lt;...&gt; my mother found out, she found out [but] not from me. I could not say it somehow, I was waiting for a suitable moment but she found out from my physician. And how the physician could say that, I don’t know.</td>
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<td><strong>Non-awareness of PLHIV about the safety precautions that are mandatory for medical specialists</strong></td>
<td></td>
<td>&lt;...&gt; I did not like that they were putting on gloves when touching me, although there are no open wounds, there were no open wounds, and it was a simple procedure, I don’t know, if something had to be touched, to see whether there is pain in the liver or not. She put on gloves, even though there was a patient before me, she did not put those gloves on.</td>
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## Limitations experienced by PLHIV

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<th>Occurrence</th>
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<tbody>
<tr>
<td>Obstacles created by the physician for the hospitalisation of the HIV-positive person</td>
<td>I go to the physician and he offers something that I am already aware of. In fact, there is an obstacle, for example, to be hospitalised, or to go somewhere, all the more since I am also a drug addict.</td>
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<tr>
<td>Institution’s conscious “getting rid of” the HIV-positive person by the institution</td>
<td>(&lt;...&gt;) they treat people differently. For example, there was a case with my mother. My mother was running a very high temperature. We used to call the emergency medical service, they would come, hospitalise her, and when they found out that she had HIV, they would discharge her immediately.</td>
</tr>
<tr>
<td>Conscious behaviour of medical specialists that provides little help to the HIV-positive person</td>
<td>(&lt;...&gt;) There was one acquaintance who had severe pain in her stomach, she also had HIV, she had cancer as well... she had severe pain in the stomach, we called the emergency medical service, as soon as they understood that she is infected with HIV, they said that there was nothing they could do, made an injection and left... the medicine did not help at all...</td>
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## Stereotypical attitudes of medical specialists towards HIV-positive persons

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<th>Occurrence</th>
<th>Description</th>
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<tr>
<td>Unprofessional behaviour of the physician by putting the label of a drug addict on PLHIV</td>
<td>I had surgery on my leg when it was broken. I went to the doctor at the outpatient clinic, showed him my leg, and told that I have HIV. I didn't even have a chance to start to explain the problem... And I put a paper on the table, a hospital record certifying that there had been an operation on... due to a fracture, etc. Without even reading this paper, he established the diagnosis – trophic ulcer, and that I am a drug addict. It was a shock to me... A person has immediately concluded... heard that I am infected and seeing this brown spot on my leg... But that was after the surgery because they had cut the skin and it did not heal well... He determined that this may be caused by a needle which I have put there somewhere, and this caused a reaction. And later, only after I asked him to read the record and had introduced myself that I am (&lt;...&gt;) then, of course, he was shocked... He read it immediately and apologized... this shows the attitude. Once you say that you are infected with HIV, and they immediately establish the diagnosis: you are a drug addict.</td>
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**Being aware that a person is HIV-positive and dependent on drugs, the family physician and the surgeon do not create preconditions for inpatient treatment even though the person is not using drugs anymore and has an accompanying disease – thrombophlebit.**

The stories of the study participants highlight the informal attitude prevailing in health care institutions in respect of PLHIV, which is “less contact, less problems”. The mother of one of the study participants had HIV as well, and he knows from his experience that contacting medical specialists after openly disclosing one’s HIV diagnosis equals ensuring that no health care services will be provided:

\(<...>\) they treat people differently. For example, there was a case with my mother. My mother was running a very high temperature. We used to call the emergency medical service, they would come, hospitalise her, and when they found out that she had HIV, they would discharge her immediately. [research participant (18) T]

The behaviour of medical specialists described above humiliates the dignity not only of the HIV-positive person but also of the professional medical community and at the same time encourage the social exclusion of the HIV-positive person in the medical community. However, another fact that the attitudes of many study participants are tendentiously negative concerning medical specialists, for example, when they talk about situations about the gloves put by medical specialists while examining the infected person’s body or performing procedures, should be mentioned as well. This shows that PLHIV are extremely sensitive to their health situation and look at every action of a medical specialist in a hyperbolised way, without objectively assessing a specific situation where there are no elements of humiliation of dignity or discrimination.

**Do you know any examples of discrimination from the experience of other PLHIV?**

The study participants themselves have not experienced any malicious attacks by society but they have heard about the negative behaviour of PLHIV themselves – physical violence and rapes of women in order to infect others as well. However, such examples are rare and show the radically deviant and violent manifestation of the behaviour of HIV-positive persons.

There are also cases of discriminatory behaviour by medical specialists, for example, when they consciously avoid transporting the HIV-positive person from the rehabilitation centre to the hospital and ask assistance from other medical specialists; thus,
the person’s complicated health condition is ignored arguing that “it has been the same for such a long period of time, so it is not hard to wait a little longer...” [research participant (6) F]  

One respondent has told from her own experience that when she was hospitalised, she was given a separate room but a sign with the word “HIV” was placed on the door. This caused great moral and psychological discrimination against the HIV-positive woman: the medical personnel behaved unprofessionally by going to look at the diseased person as a “different, special” individual in a negative sense, and the person herself did not feel as having a disease but felt as someone who

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<tr>
<td>Presumptions regarding untold discrimination experiences of PLHIV</td>
<td>Secrecy of discrimination experiences</td>
<td>Yes, that no assistance would be provided I have not heard of but &lt;...&gt; I have heard only that there are a few persons whom I know, they are also infected with HIV. I have heard only that one of them has sexual relations with women and he wanted either to rape the wife of one acquaintance, or something like that... maliciously...</td>
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<tr>
<td>Facts on the malicious behaviour of PLHIV existing in society</td>
<td>Physical aggression of PLHIV</td>
<td>&lt;...&gt; the last examples are from rehabilitations where there were four of us with HIV, and nobody took us to hospital, even though a person had been running temperature for a month. They said “you have been running that temperature for so many years, that it can be like that a little longer, nothing will happen to you...” this one is of the most recent examples.</td>
</tr>
<tr>
<td>Discriminatory behaviour of medical specialists towards PLHIV</td>
<td>Conscious avoidance of transporting an HIV-positive person to hospital by ignoring their serious health situation</td>
<td>when I was hospitalised for a burn.... I was given a separate room and physicians would rarely come to visit me..., and on my door HIV was written in the biggest letters. They simply underlined it with a pen, so it was very visible, and when I took off the card, they told me I had no right.... Everybody would come to look...All nurses were pointing fingers at me, all of them groaned...oh... oh... In short, they were pointing their finger at me... That’s how I remember that one of the first shocking moments. After that nothing has shocked me...</td>
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<td>Violation of the principle of the patient’s confidentiality, which has caused psychological an moral discrimination of the HIV-positive person in hospital</td>
<td>Yes, others have also experienced the same problems. The majority with whom I have talked. Yes, my acquaintance was also hospitalised, his leg was festering. And nobody wanted to touch that leg. He was hospitalised...and that’s it... It was totally horrible with that leg.... He said that when he wanted to receive some help, he almost had to shout with a loudspeaker, to speak in a raised voice...so that somebody would pay attention to him.</td>
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<td></td>
<td>Conscious ignoring by medical specialists of the HIV-positive person’s health situation by avoiding to provide the required aid</td>
<td>Also, there was the case with the woman who suffered pain in her stomach. It was the last stage of cancer. They did an echoscopy for her, found nothing and told her that she suffered pain because she was injecting somewhere in the groin. The third stage of cancer, spread everywhere, the largest, when the gynaecologists examined [her] a week later. He said I don’t need any tools, I can see that cancer already. And here they could not see it in an echoscopy. They did not want to see it.</td>
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<tr>
<td>Failure of medical specialists to protect themselves is the manifestation of unprofessionalism</td>
<td>Disposable gloves not worn by the nurse</td>
<td>&lt;...&gt; when I was hospitalised &lt;...&gt; the nurse took blood from my finger for tests without gloves and immediately went to another person... I shouted at her “what are you doing here?” They know the whole description of my diseases, they know that I have a hepatitis and HIV and goes around without precautions.</td>
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is isolated, a leper. Such examples show that not only society but also medical specialists are not ready to accept PLHIV as full-fledged members of society that have a specific disease:

<...> when I was hospitalised for a burn..... I was given a separate room and physicians would rarely come to visit me..., and on my door HIV was written in the biggest letters. They simply underlined it with a pen, so it was very visible, and when I took off the card, they told me I had no right.... Everybody would come to look....All nurses were pointing fingers at me, all of them groaned...oh...oh... In short, they were pointing their finger at me... That's how I remember that one of the first shocking moments. After that nothing has shocked me...[respondent (16) R]

There is another example illustrating how medical specialists avoid providing the required aid to an HIV-positive person, thus humiliating the dignity of this person:

Yes, others have also experienced the same problems. The majority with whom I have talked. Yes, my acquaintance was also hospitalised, his leg was festering. And nobody wanted to touch that leg. He was hospitalised...and that's it... It was totally horrible with that leg..... He said that when he wanted to receive some help, he almost had to shout with a loudspeaker, to speak in a raised voice...so that somebody would pay attention to him. [respondent (16) R]

The majority of the study participants have not indicated that they have experienced discrimination from medical specialists. One case reveals the lack of knowledge of medical specialists, which can cause negative consequences for them and other patients:

<...> when I was hospitalised <...> the nurse took blood from my finger for tests without gloves and immediately went to another person... I shouted at her “what are you doing here?” They know the whole description of my diseases; they know that I have a hepatitis and HIV and goes around without precautions. [research participant (17) S]

The failure to maintain confidentiality by medical specialists shows their unprofessionalism and naturally creates preconditions for the social exclusion of PLHIV:

<...> a woman, God rest her soul, was hospitalised in one clinic <...> when I went out to the corridor, I personally heard when two grandmothers were standing and saying: “the infected drug addict is here”. So, most probably, the grandmothers have not taken this out of nowhere. [research participant (20) V]

**What could health care personnel do to facilitate access for PLHIV to health care services?** When communicating with medical specialists, PLHIV expressed the need for positive, non-categorical attitudes and equal treatment, which is an important manifestation of emotional intelligence of health care specialists. The study participants emphasised that medical specialists must provide detailed information about institutions where one can receive information and help, and there is a huge demand for specialists who have acquired professional qualifications to consult, teach and inform PLHIV on various issues. HIV-positive persons claim that they expect higher sensitivity and ability of empathising the situation of the diseased, as “you can understand it only inside” (research participants (1) A, (9) J). They stated that medical specialists must be educated and trained on HIV / AIDS. They expressed an opinion that HIV must be treated like cancer, TB – as a chronic and incurable disease because this would create preconditions for health care that is more accessible to PLHIV. The research participant tells from her experience that physicians themselves exclude PLHIV after they have informed them about their disease. Having received information from the HIV-positive person, physicians become arrogant, which reveals their unprofessionalism, and their verbal communication and behaviour stimulate the social exclusion of the diseased:

*That they would act like medical workers. They took a Hippocratic oath, and the physician must be a physician rather than select patients for himself or herself. And physicians choose patients, and we remain unwanted. Especially... I am hospitalised*
now I told the physician when he came that I have HIV, I expected more attention and he said... Be happy that somebody comes to look at you because for the money we receive, soon nobody will come at all. [research participant (61) R]

In the stories provided by the study participants, there is a need to develop the comprehensive competence of medical specialists, a competence that encompasses tolerance, consciousness, and a deep, accurate, and scientifically based medical knowledge of HIV/AIDS.

**Are health care specialists ready to adapt to the needs of PLHIV?** The research participants claim that the health care system has not adapted to the needs of HIV-positive persons yet, and they express this by saying that they have to look for a medical specialist who would agree to pull out a tooth or operate on the HIV-positive person, knowing the diagnosis. The interview participants understand that workloads for physicians in the health care system do not allow for paying greater attention to PLHIV, and there is a need of PLHIV for physician consultations and conversations about problems arising in connection with health, psychological or social issues. The research participant who gave birth more than once while being infected with HIV experienced a situation where her dignity was humiliated in relation to a gynaecologist, and such behaviour of physicians deepens the social exclusion of HIV-positive persons:

Yes, I had. With a gynaecologist. There was a noise. She opened the door and started to shout, this is not your first childbirth? Who can give birth to children with such test results? Infected with HIV! And so loud... I am asking, doctor, why are you shouting, there is a queue waiting outside the door. And she [said] - “Why shouldn’t I shout? What are you thinking, giving birth to sick children?” That’s what it was like. [research participant (16) R]

The fear experienced by the HIV-positive person for herself and the child creates preconditions for insecurity in society, for example, the study participant states that her child’s paediatrician does not know her HIV diagnosis just so the child can be protected from discrimination and social exclusion:

We live in a small town. <...> One person knows, then the whole town knows. Not that I would conceal my HIV status. I am protecting myself and my child from difficulties. [research participant (17) S]

**Experiences of HIV-positive persons in the Health Care System**

**Health disorders causing physiological, psychological or social discomfort are characteristic of PLHIV.** PLHIV often experience negative health conditions such as excessive sweating, weakness, fatigue, physical and intellectual exhaustion, lack of appetite, vesicular skin rashes, constant sensation of heat, leg pains, long-term depressive states, digestive system disorders, seborrhoea, excretory system disorders, and enlarged lymphatic nodes. The aforementioned symptoms are particularly typical of PLHIV who have had this disease for several years and have been taking antiretroviral medicines. PLHIV who have been diagnosed with the disease one to two years previously state that their health status is good – they very rarely get sick with infectious diseases or colds. However, PLHIV suffer from associated diseases which they have had before their HIV-positive diagnosis or which have occurred after this diagnosis. This is why in finding strength within themselves, PLHIV empower themselves for a life in a constant routine by taking medicines, keeping a nutritious diet, engaging in physical activity and psychological self-management, because only systematic and continued work with oneself creates preconditions to survive physically and psychologically by assuming responsibility for the quality of one’s life.

**Demand for medical assistance and advice.** The participants in the study understand the need to maintain their health but the main barrier in addressing specialists is their poor financial resources or the absence of financial resources. Consulting a family physician, an infectologist, and an odontologist is the most important
thing for PLHIV to do. Maintaining contact with a gynaecologist is very important for HIV-positive women. Due to the associated diseases that occur, PLHIV have to visit a cardiologist, an oculist, and a surgeon. A substantial number of PLHIV do not contact medical specialists and prefer to rely on information and support provided by their friends. This PLHIV opinion is limiting and caused by the fear and negative attitudes that are very strong in society. In Lithuania, there is a need for positive HIV prevention, i.e. treatment must be prescribed as early as possible and PLHIV must be educated about the mandatory systematic use of medicines and negative outcomes of the non-systematic use of medicines for the body. For this reason, there is a need for professional psychosocial assistance for PLHIV. A respectful and objective behaviour of health care specialists is important for PLHIV because the cases of inadequate behaviour, emotional reactions, negative attitudes expressed consciously or preconditions created by physicians and/or nurses to restrict access of health care services to PLHIV humiliate not only the human dignity of PLHIV but also the professional dignity of the professional medical community.

Demand for the development of competence of health care specialists in the field of HIV/AIDS. Low awareness of HIV/AIDS issues among medical specialists determines their fears, anxiety and inadequate emotional reactions and behaviour when coming face-to-face with an HIV-positive person. In such interactions, medical specialists in health care institutions tend to label PLHIV without adhering to the principles of respect for personal dignity and confidentiality, while PLHIV experience external pressure, moral humiliation, social and psychological exclusion, prompting PLHIV to feel internal self-remorse, feelings of guilt and shame. The lack of knowledge on HIV of medical specialists causes not only their psychological insecurity (for example, when “HIV” is written on the door of a separate room) but also a danger to their own health and the health of other patients (for example, when blood taking procedures are carried out without disposable gloves and then the same procedures are immediately repeated with another patient without gloves again). Thus, the non-competence of medical specialists on HIV/AIDS issues result in the moral and psychological discrimination of PLHIV and the humiliation of the dignity of the professional medical community caused by medical specialists themselves. Therefore, there is a need for the development of the emotional intelligence of medical specialists, their self-empowerment for the change in attitudes, equal treatment of PLHIV, goodwill, sensitivity, and empathy.

Readiness of health care specialists to adapt to the needs of PLHIV. The health care system has not adapted to the needs of HIV-positive people yet: workloads for physicians in the health care system do not allow for paying greater attention to PLHIV, and there is a need of PLHIV for physician consultations and conversations about problems arising in connection with health issues, psychological issues or social issues.

PLWHIV individual experience by interacting with Non Governmental Organizations (NGOs)

What kind of social services do you need/lack most? Where PLHIV have a low income and they need to pay for dwelling and medicines, sometimes they are short on food and sometimes they are short on clothing. However, in this case target organisations can help such as the Red Cross. The study participants expressed their needs for social support, dwelling services, and discounts on medicines. However, such possibilities can be available only where an HIV-positive person has disability status. This often means the public disclosure of the diagnosis, which HIV-positive persons avoid and are afraid of. There is a closed vicious circle between the needs of PLHIV, stereotypical public attitudes, assumptions of PLHIV of social exclusion, and limited possibilities of institutions to help without having precise information about the person’s health status associated with the HIV diagnosis. HIV-positive individuals state that they need insurance, which would create preconditions for better access to physicians.
**Did you need / do you need a psychologist’s assistance?** The respondents stated that the demand for psychological support is particularly relevant after one has been diagnosed with HIV. Sometimes this kind of assistance may be provided by a general practitioner who is competent in the field of psychology and is a sensitive and empathic person. A psychologist’s assistance is very important but it has to be urgent – provided at that particular time when a person needs it. Now, a psychologist has working hours and an HIV-positive person has to adapt to the psychologist’s work schedule. PLHIV are not satisfied with such a situation – they express the need to have possibilities of choosing from several psychologists, so that there is a specialist with whom they can discuss emotional and psychological problems at any time they want.

Not all the study participants express the need for assistance from a psychologist or psychiatrist. Some of them claim that psychological support received from an HIV-positive person who provides information based on his or her life experience is the strongest and most effective psychological help, and not from a medical specialist. This empowers others to motivate themselves for work, life, and positive attitudes. One of the study participants admits that after the establishment of the diagnosis he became ill with depression and needed a psychiatrist’s help. This specialist helped at least a little bit to overcome the state of depression and manage his anger and emotional aggression. The stay in the rehabilitation centre for some PLHIV is meaningful not only in terms of communication with the “brothers of the fate” but also in terms of satisfaction of the needs for timely specialist assistance.

The research participants who are not inclined to contact psychologists for help claim that they deal with arising psycho-emotional difficulties on their own. Friends can also successfully play the role or function of a psychologist. The majority of the study participants believe that the function of a psychologist can be performed by any person who is able to listen and discuss, and who is a good conversationalist – such communication serves as a certain kind of psychotherapy.

**Did you need / do you need the services of a social worker?** The research participants express the need for a social worker, particularly when processing required documents. A social worker is also necessary for giving advice to PLHIV on the alternatives, ways and realistic possibilities of dealing with social problems. The interviewees who communicate with social workers claim that this specialist helps recover emotionally and provides psychological help.

Some HIV-positive persons have expressed the need for the social worker’s services; however, they have yet to use them. They did not provide comments as to what kind of services those are and why they do not use them. Other research participants have not come across life problems; and therefore, they don’t express the need for social services and a social worker’s assistance. In addition, they don’t know that a social worker is a specialist who acts as an intermediary in assisting people to receive social services. However, an HIV-positive person does not consider this situation to be non-awareness – the interviewee has not come across the need for such services and he or she did not look for the social worker’s help either.

**Who should offer services to PLHIV – an NGO, the Government, the private sector, or the church? What kind of services must be provided to PLHIV free of charge?** HIV-positive persons claim that the fundamental help to a person diagnosed with HIV is moral, spiritual, one received through faith. And assistance provided by other organisations should first of all have a purpose that is moral rather than financial, then it will be meaningful. Some study participants do not believe that the church is the sector which can help PLHIV, and they have the same opinion about the private sector as well. There is a need for the distribution of functions between organisations providing assistance and support so that actual results could be seen. They believe in the effectiveness of NGOs because these organisations are independent, and in general “good-natured people work there” (research participants (1) A, (3) C). The effectiveness of NGOs is based on the fact that they are comprised of persons who perceive the problems and needs of PLHIV best and can reasonably demand help for people, to provide information to the public, and act as intermediaries.
Table 10. Possibilities of Supply of Services for PLHIV from Various Sectors

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<tr>
<th>Category</th>
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<tr>
<td>Need for activeness of governmental institutions</td>
<td>Demand for special services</td>
<td>“&lt;&gt; it would be good to obtain all information related to treatment, particularly regarding jobs, so that it would help a person &lt;&gt; from the municipality &lt;&gt; Maybe there should be a separate office.</td>
</tr>
<tr>
<td></td>
<td>Confidence in governmental institutions</td>
<td>I think that governmental ones are the best, I don’t know, so that people donate money or something here... what here...</td>
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<tr>
<td></td>
<td>Demand for the initiative of the government</td>
<td>Well, from a governmental one. Because everywhere in non-governmental ones it is paid for and you must have money.</td>
</tr>
<tr>
<td>Preconditions for the effectiveness of an NGO</td>
<td>Target NGO understand the needs of particular groups best</td>
<td>I would think that the greatest task is for the NGO sector to provide services. There is only one reason for this – they are patient organisations and they understand best because that is their essence – they understand best what other people need. I will go to the doctor, well, the doctor will talk, make it sound nice, add something else, take something out and it will be a mess, and I will not get anything out of this. And NGO is a totally different thing. You go there and know that you will receive help, that you will not be left at the door, that nobody will get rid of you.</td>
</tr>
<tr>
<td>Need for particular organisations to distribute activities and functions between themselves</td>
<td>Faith is the essence for an HIV-positive person</td>
<td>When you were reading the question, the thought that faith is very important came to my mind immediately.</td>
</tr>
<tr>
<td></td>
<td>Primary help is not associated with money</td>
<td>It is really not important to me who and how much, and what organisation will provide what kind of help, the most important thing for me, the first thought was that they would not do this for money. This would be perfect because money can run out or something else... there might be some nuances and then what – will all kinds of assistance disappear?</td>
</tr>
<tr>
<td></td>
<td>Demand for the effectiveness and productivity of organisations providing assistance</td>
<td>Everyone can contribute to this matter, for a good purpose, but just so it would not be mixed, that, for example, one organisation assumes a lot of activities and in the end does not do anything… so it should be specifically distributed who is doing what. Tangible works, and a tangible result shown.</td>
</tr>
<tr>
<td>NGO activity – the most effective assistance to PLHIV</td>
<td>Independence of NGOs is the precondition for effectiveness in providing assistance to HIV-positive persons</td>
<td>I think that these services would be best provided by non-governmental organisations. Because, as a rule there are very good-natured people working in such organisations. I cannot imagine how, for example, the church could help because the church most probably considers intimate relations to be a sin. So what else can they do to help? &lt;&gt; But I think that non-governmental ones, they have many possibilities. The state one, then it will be as always – if financing is allocated, then this money will be channelled somewhere and the problem and &lt;&gt; the service will be overlooked and it will not do any good to anybody.</td>
</tr>
<tr>
<td>Impact of information published on the Internet on PLHIV</td>
<td>Danger of information published on the Internet for PLHIV who don’t have knowledge about their disease</td>
<td>And by way of direct communication, and in respect to psychological support. And speaking about the Internet, I think that the most stupid thing for people is to use information on the Internet – this is the most stupid thing because there is so much written on this Internet and there are so many lies that... During the first months after one has heard about that virus, it is better not to go on the Internet and see because just having read what is written there, one can jump out of the window.</td>
</tr>
<tr>
<td>Role of the church in respect of PLHIV</td>
<td>“If you want to receive support from the church, you need at least to be a believer”</td>
<td>I don’t know if the church needs that. If you want to receive support from the church, you at least need to be a believer.</td>
</tr>
<tr>
<td>Provision of spiritual support to HIV-positive person</td>
<td>The church could offer spiritual assistance because still people are believers. Maybe a person cannot go to the psychologist to let everything out, he or she can go to a priest.</td>
<td></td>
</tr>
<tr>
<td>Participation of the private sector in providing assistance to PLHIV</td>
<td>Capability of the private health care sector in providing assistance to PLHIV</td>
<td>I think that the private [medical] sector should provide more because there are more qualified physicians there, higher qualifications. Physicians who work in state institutions, well.. I don’t say that all of them are bad, but the majority of them are...</td>
</tr>
<tr>
<td></td>
<td>“If you pay, you will get help in any case”</td>
<td>The private sector is a business structure. So, if you pay, you will have it in any case – whether you are infected or not infected. So, I don’t think that a business structure could do something in this case... that they should be forced to do something because again this is not relevant to them.</td>
</tr>
<tr>
<td>Need for initiative by PLHIV for personal welfare</td>
<td>Need for self-care of PLHIV regarding work and learning</td>
<td>No, the HIV-positive person himself or herself must go and search for what he wants for work or studies... The person himself or herself must be interested in this. If he is not interested, what is the use of offering it to him.</td>
</tr>
</tbody>
</table>
Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

Distrust in the private sector

<table>
<thead>
<tr>
<th>Assistance from the private sector – a precondition for an HIV diagnosis, seen as a misfortune, to be used for making a profit</th>
<th>Because the commercial one will only start making money from us.</th>
</tr>
</thead>
</table>

Need for cooperation between the government, an NGO and the church in providing effective assistance to PLHIV

<table>
<thead>
<tr>
<th>Resources and possibilities of the state</th>
<th>As I am acquainted with this situation and with services, I can say that all institutions must provide them, but by cooperating with each other. Let’s start with the first. The state has sufficient resources and possibilities.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>The non-governmental sector – a source of motivation and knowledge</th>
<th>The non-governmental sector has sufficient levels of motivation and knowledge, but they don’t have the resources and possibilities.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>The church – a source of spirituality</th>
<th>The church should be the source of spirituality, and the church, currently Caritas, does a lot under ex-convict integration, the homeless and prevention of violence against mothers programmes, there are rehabilitation centres. The church does a lot in that direction. Through spirituality, it can be said, and the formation of the family… They are also doing that thing.</th>
</tr>
</thead>
</table>

between PLHIV and politicians. The respondents claim that governmental organisations should show initiative at least in the provision of information about HIV treatment services – what is paid for, and what is free of charge, where to apply, etc. The interview participants emphasise that information published on the Internet may be harmful, when a person does not have accurate professional information and deep knowledge of his or her disease.

*During the first months after one has heard about that virus, it is better not to go into that Internet and see because just having read what is written there, one can jump out of the window.* [research participant (7) G]

Therefore, information and advice provided by professional medical specialists are a must. It is important for PLHIV to take care of their own learning, professional career and job search, i.e. the person himself or herself must show initiative. In their contributions during the interviews, the study participants emphasise that there must be cooperation between the government, NGOs and the church, working together, and not separately:

*Practically, I could not distinguish a single thing [of] what should be done by whom. There must be joint work. If we start doing it separately as it has been up until now, then we can see that there has been nothing good. In other words - close cooperation.* [research participant (20) V]

*What could be done by NGOs so that NGO services would be more accessible to PLHIV?* NGO activities can be seen through the communication and organisation of self-help groups. NGOs are considered by many study participants as the intermediary in receiving spiritual support, the context of social communication. Furthermore, the study participants consider NGOs to be intermediaries in providing financial support and residential premises to PLHIV.

In small cities, towns or villages, PLHIV do not have any possibilities of receiving consulting and accurate information or contacting a medical specialist according to their needs. The main problem is not the reluctance of an HIV-positive person to consult specialists but the lack of specialists who could provide help on specific issues. The provision and receiving of information at any time as well as the presence of persons who can be approached for assistance in certain centres is an essential need of PLHIV. Very often one only needs to obtain information by telephone. In addition, it is also important that NGO would initiate groups of PLHIV, encourage PLHIV to participate in the rehabilitation communities for drug addicts or alcoholics, where they can receive emotional support and talk openly with other persons who have had similar experiences. Some HIV-positive persons consider NGOs to be not intermediaries but direct providers of services (social and/or educational); therefore, it is important for these organisations to keep their members.
The study participants state that AIDS centres must be established in both big cities and small towns – they are the chances of PLHIV to obtain necessary information and assistance, to come for tests, etc. In this way they would also become a centre for PLHIV to gather and where they could share their experiences and disseminate information.

**What could PLHIV themselves do in Lithuania to make their life better?** PLHIV initiatives are important: to share information when initiating meetings that disseminate information, and to discuss and defend the rights of PLHIV. The mutual concern of PLHIV is first of all understood as sharing information, i.e. continuous targeted contact. Thus, they don't feel rejected or unneeded and naturally integrate into social networks. The research participants state that the personal experiences from PLHIV themselves are very valuable because “everyone passes challenges” [research participant (20) V] and “sharing one’s experience is more important than precise information about HIV” [research participant (3) C]. This goes much deeper – it is not information but the experiences of the person who has the same problem, the same health situation, which allowed for the experiencing of what is effective and what is not, what is needed and what is not, etc. Some study participants are sceptical about the open disclosures of PLHIV, the desire to become “public persons” – this more often results in negative outcomes for PLHIV than positive ones, according to several interview participants.

**What could be done by the country’s government in order to improve the life of PLHIV?** The research participants state that the government’s attention is important because it is an institution that has the power and can make an impact. There is a strong stereotypical attitude entrenched in society towards PLHIV as people that are “written off”. They cannot advertise that they are supported by some organisations or famous people – this would be anti-advertising for both organisations and individuals; therefore, such facts are suppressed as “a silent mutual agreement”. HIV-positive persons raise the question that those who have cancer or other serious chronic diseases receive a lot of attention and the HIV diagnosis alone causes exceptionally negative emotions. This means that society is incapable of tolerating and being empathetic. In this context, a need arises for the government’s support (not financial but moral) through information, visits to PLHIV, etc.

The study participants claim that financing is undoubtedly important but the result must be oriented precisely towards PLHIV. For example, brochures are published but they contain information about the ways of HIV transmission and still this information is not always deep and accurate, but just general information. Brochures of a different nature – showing the positive life cases of PLHIV: what assistance has been provided and how effective it was, what specialists there are and how they were helped, perhaps somebody found a dwelling successfully – should be published as well. This means that there is a demand for information about positive cases from the lives of PLHIV. Some of the study participants are frustrated with themselves – they don’t blame their environment, they perceive that drug use is a horrible addiction but they don’t have the will to withdraw from it; therefore, they think that the best way out would be “What good can I do for Lithuania? To die faster so that I am not in the way” [research participants (1) A, (9) J].

Cooperation between the government and NGOs is particularly important because, according to some study participants, there is no transparent public procurement mechanism applied in the implementation of the programmes that are relevant to PLHIV; a clearer and more efficient mechanism for the government’s support to NGOs through programmes, projects and public procurement is needed.

**Experiences of PLHIV in Various Environments and Interactions**

**Need for social services for HIV-positive persons.** Because of low levels of income, PLHIV have problems to make their housing payments and purchase food or clothes. A need arises for PLHIV to receive social support for house-related services and discounts for medicines which may be applied provided that PLHIV have disability status. The latter often means making their diagnosis public, which PLHIV
try to avoid and are afraid of. In this background, there is a flawed circle between the needs of PLHIV, stereotypical attitudes of society, and assumptions by PLHIV about the social exclusion and restricted possibilities of various institutions to assist without knowing precise information about a person's health condition related to the HIV diagnosis.

**Need for psychological support for HIV-positive persons.** The demand for psychological support is particularly acute and urgent when a person finds out about his or her HIV-positive diagnosis. In this case, PLHIV need a listener rather than a moralizer, silence rather than targeted questions, sensitivity and empathy rather than instructions on the life strategy, consulting according to need rather than consulting based on the work schedule of a psychologist. In this context, there is a need for the development of competence of psychologists on HIV / AIDS issues, strengthening of social competence, and enhancement of emotional intelligence. It is also important to have a telephone line orientated towards HIV-positive persons, by which they could obtain replies to questions that are relevant to them confidentially and anonymously. Without obtaining timely moral support and psychological backing, an HIV-positive person experiences complicated psychological and emotional stress, with which he or she can hardly cope on his or her own, and he or she needs a psychiatrist’s consultation, and sometimes a few months of treatment by psychotropic medication. In absence of professional assistance, HIV-positive persons are content with their friends’ support and moral backing, calling it a kind of “specific psychotherapy”. However, such a situation does not resolve the problem related to the absence of the psychological support system for PLHIV, but merely deepens it.

**Need for social work services for PLHIV.** Social work services are important when obtaining required documents and providing advice to PLHIV on the alternatives, ways and actual possibilities for dealing with social problems. A social worker helps PLHIV regain emotional strength and provides psychological support.

**Experiences of PLHIV in penitentiary institutions.** In penitentiary institutions, HIV-positive people are isolated by allocating them a separate cell, which has an impact on their psychological exclusion – other people in penitentiary institutions treat them as “different” or “exceptional” in a negative sense. In penitentiaries, there is a lack of physicians, their workloads are enormous – the number of people who have various diseases is very big, and therefore the physician has no possibilities to provide assistance to all and in a high-quality manner. In correctional institutions, there is a demand for informal consultants who are HIV-positive themselves and can share their experience with PLHIV held in penitentiaries. The spread of the living-with-HIV experience and submission of accurate information about HIV / AIDS to imprisoned persons is an excellent alternative to a psychologist’s consultations, where there is frequently a lack of specialist understanding in the field of HIV / AIDS specifics.

**Possible trends in rendering services to PLHIV.** Non-governmental organisations (NGO) are among the most efficient organisations, which may initiate intermediate and represent HIV-positive persons. NGOs are effective because there are people who understand problems and needs of HIV-positive persons and may demand assistance for them in a reasoned manner, provide information to the public, and act as an intermediary among HIV-positive persons and politicians. NGO activity is exceptionally relevant in demonstrating initiative to provision of information about HIV treatment services and selection of general information about HIV / AIDS because information available on the Internet may cause great emotional, moral and psychological damage to a person, who experiences an emotional shock about their recently diagnosed HIV, and the consequences for an HIV-positive person may be manifested in depression, cause suicide or return to the former harmful lifestyle without enabling them to take responsibility for the quality of their life and spontaneous decision to practice additionally as many addictions as possible, pursuing to a “more speedy end”. The role of the church could be reflected by spiritual assistance and the moral backing of HIV-positive persons. However, cooperation...
between the government, NGOs and Church is needed by working together, and not separately.

**NGO assistance to HIV-positive persons.** NGO activities should be carried out through communication and the organisation of self-help groups. NGOs are considered to be an intermediary in providing moral and financial support or residential premises to PLHIV. Being in communities where there are HIV-positive persons, they will have possibilities of talking about their problems openly, obtain new information, get emotional support, and acquire a different emotional experience, which will allow them to become stronger emotionally and psychologically. NGO initiatives are important in promoting the establishment of AIDS centres in large and small towns, which is a primary opportunity for an HIV-positive person to obtain the appropriate information and assistance or register for medical examinations. Such centres would have the potential to become gathering centres of PLHIV, where HIV-positive persons could share their experiences and feelings and discuss problems and possible strategies of their solutions.

**Need for initiatives by PLHIV.** PLHIV can help themselves and other HIV-positive people by revealing their experiences, sharing the most recent information, participating in conferences on HIV, and maintaining contacts with organisations representing PLHIV, particularly with NGOs, i.e. targeted mutual contact among PLHIV is necessary. This does not allow an HIV-positive person to feel separated or unneeded. The experiences of PLHIV are the most valuable information for other HIV-positive persons, which, in most cases, may be a stimulus to change his or her life strategy towards the positive, enable himself or herself to take care of their personal health protection, assume responsibility for his or her life quality, by empowering himself or herself to learn, study, acquire professional qualifications, etc. However, an HIV-positive person needs courage, strength and will for the above-mentioned aspects to enable himself or herself to have this information known to the public due to the HIV diagnosis and the difficulty in breaking through the stereotypes in society not revolutionarily, but evolutionarily, encouraging society to recognize an HIV-positive person not as a diagnosis, but as a human being who has feelings, experience, abilities, and talents, without projecting HIV stereotypically onto the context of risk groups. There is a need that exists in the context of HIV/AIDS to avoid using the term “risk group”, which is discriminatory, but to use “sensitive group”, which is flexible, and does not create preconditions that influence one’s view.

**Need for government’s attention in creating preconditions for improving the quality of life for PLHIV.** People who have cancer or other chronic diseases receive a lot of attention from the government, whereas an HIV-positive diagnosis causes particularly negative emotions, which shows that the competence of Lithuanian society in terms of tolerance and empathy is low. In this context, PLHIV have a need for moral support from the government through information, media, visiting PLHIV, etc. Furthermore, there is a need to monitor and control the target use of funds allocated by the government to projects, because the products obtained as a result of these projects often lack quality and effectiveness. Cooperation between the government and NGOs is especially important, because there is no transparent public procurement mechanism applied in the implementation of the programmes that are relevant to PLHIV; a clearer and more efficient mechanism for the government’s support to NGOs through programmes, projects and public procurement is needed.
SECOND STAGE OF THE QUALITATIVE RESEARCH – FOCUS GROUPS

Perception and Attitudes of Specialists Working in the Educational Sector about HIV and HIV-Positive Persons

What feelings and thoughts are associated for a person diagnosed with HIV? Most of the participants state that the first thought upon hearing about an HIV-positive person, is associated with the person’s fatal end, so the first feeling is compassion for an HIV-positive person. However, thinking about a real encounter with an HIV-positive person, the education system specialists state that they would experience preliminary anxiety due to possible communication with an HIV-positive person – they would not know what to say and how to behave. This is why the group interview participants state unanimously that there is a need for objective information not only about HIV/AIDS but more about the various experiences of PLHIV. There is no information like this at present, which is why education specialists would not be able to render psychological support at this time. Incorrect information is a premise for PLHIV to experience stigma and fear to say his or her diagnosis to their environment while being afraid of exclusion. The research participants state that even medical specialists in this context often cannot help to cope with the situation competently and positively socially, but they create preconditions for self-reproach, leaving the person without consultation, the provision of information and moral support:

Believe me, there has been incorrect information, and the problem remained, and I surf in the Internet. I found <...> information. Later on I found out that everything was OK... So I can imagine what it can mean to a person, who has been infected with this disease... [social pedagogue]

What moments are emphasised to students when presenting HIV as one of the social problems? The analysis of the focus group interview revealed that medical specialists (most frequently a school nurse) provide information on the ways of HIV transmission and its prevention to students; however, it is not effective because such sessions take place rarely, information is submitted fragmentally, and there is no continued provision of the most recent information on HIV by age group:

Statistics... Yes, you give statistical data... Informational moments... [nurse]

Although not very often, certain campaigns promoting solidarity and tolerance among students are carried out in schools:

<...> there are campaigns <...> as for solidarity, there is Red Ribbon Day, we draw various posters, best options how to deal with other people and support them morally... [social pedagogue; social worker]

Social exclusion of HIV-positive children in school: is this a fact that exists or a possible premise? The specialists working in the educational sector state that it has been avoided in schools to recognise HIV as a reality, which already exists. Avoidance is expressed as an avoidance of discussion about HIV on a school wide scale, and if there was such a concrete fact, then there would be, as the respondents put it, real panic:

<...> If there was such a fact that there is such a child in school...how to behave with him/her, whether it is somebody’s mother or father...[psychologist]

The participants of the discussion created a hypothetical situation of an HIV-positive child in school and state that neither teachers nor children nor a psychologist would
know how to behave with the child who is HIV-positive, or how to behave with a child, whose parents are HIV-positive, even though the child is healthy.

The group interview participants state that conversations with schoolchildren from various age groups about general values without concentrating on specific HIV problems is one of the most rational ways towards social exclusion or even discrimination of PLHIV in school and in the educational system in general. The themes of general human values should be oriented towards the strengthening of tolerance, empathy, compassion, and friendliness. Consequently, the building of students’ social competence in school may be the primary prevention against the social exclusion of HIV-positive students. The schoolmaster and the nurse stated that children should not receive the same amount and kind of information about HIV. The provision of information should be done gradually because student reactions are directly associated with their age and current life experience: older schoolchildren have a higher level of tolerance than junior schoolchildren. Also, accurate information about HIV has a great positive impact on older schoolchildren.

At what age is it important to start talking about HIV-related problems with children, and what methods are effective? The pedagogues, social pedagogues, and psychologists as well as nurses and social workers working in the educational sector state that there is a need to develop positive attitudes among students towards HIV-positive children and adults on the basis of not only accurate information about the disease and the ways of its transmission and prevention, but also based on common values without presenting HIV / AIDS as an exceptional disease because the very concept of “being different” causes social exclusion. The presentation of HIV problems should be gradual, based on the concepts of tolerance and equality. The group interview participants were divided into two groups regarding the concepts of “exceptionality” and “being different” – one of them claimed that it is relevant to present HIV-positive persons as “being different”, that only such a perception will allow students to develop tolerance and equality. The other research participants adhered to the opposite opinion, i.e. the application of the concept of “being different” directly determines the exclusion of HIV-positive people in general and of schoolchildren in particular. Therefore, it is important to develop moral values, which allow for the perceiving of the essence of human nature.

The research participants also discussed that the stereotypical attitudes existing in society influence students and one of the strongest attitudes is related to the HIV-positive person’s immoral lifestyle, the outcome of which is an HIV-positive child.

The need of punishment for immorality is very dominant in society, and it may be realized by rejecting the HIV-positive child or the child whose parents are HIV-positive at school. A social pedagogue who has been working in school for a long period has noticed:

As for me<...> I would see two different topics: i.e. one of the topics is HIV prevention, the other one is tolerance towards different people, not necessarily HIV-positive, but ones who have other diseases. As I have noticed, for children, not necessarily HIV, or adolescent, but any different kind of child, looking through their eyes, causes a problem. [social pedagogue]

Consequently, the balanced combination of medical information with the development of tolerance may provide an effective result that would allow a learner to be recognised among his peers regardless of his or her health because schoolchildren are not inclined to accept any child who has any disease. Therefore, there is a real need to develop social skills systematically and in an integrated manner at school by combining them with basic values in the school environment.

The psychologist who participated in the discussion stated that information on HIV provided to students must be well-thought out and adapted to the age, and the targeted information must be provided to children no earlier than ten years of age. However, the very beginning is the development of common values and the enhancement of social competence. The sooner the development of tolerance among children starts, the more efficient the prevention of social exclusion is, not
only in respect of PLHIV but also in respect of persons who have other diseases as well as disabled persons, because the level of children’s tolerance is higher than that of adults:

_I have also noticed, from my experience, that when it is spoken, discussed, children perhaps accept it easier than adults... for example, our school is a school of general education where healthy children study but there are disabled children who study in other schools. When my daughter was studying, there were no disabled children in the class. I took her to another school, where there were disabled schoolchildren. It was a shock to her during the first week; however, later she started telling that nobody paid any attention to it. It means that after some time the child got used to the fact that there are different people. If any disabled child came to our school, at the beginning everybody would be pointing fingers at him or her until there was some kind of prevention.... [form tutor]_

The parents of a particular child who know the child’s situation best and can present it in an understandable way, play an important role in the development of tolerance among students. However, the concept of compassion should not be an essential aspect; the essence is to treat a person as an equal member of society, without separating him or her out from among others:

<...> before that – about tolerance itself, the attitude towards a different person. Because we had a case, I do not want to mention anything specifically, when a child returned after some operation, and after his coming back he was accepted even though he was different, at the beginning we made every effort and we are grateful to parents, when they <...> talked about this disease and told about this child in the classroom with tears in their eyes... It was the outcome, to show to the children that this child should not be pitied... [social pedagogue]

The methods of student development and provision of information may be different – work in small groups, individual work carried out by the teacher, the social pedagogue or the psychologist, and projects in which teachers, schoolchildren and even HIV-positive persons could participate, taking the possibilities into consideration.

_Why does the stereotypical myth that an HIV-positive person poses a threat to society exist?_ The research participants state that the stereotypical myth about the danger or threat posed by PLHIV to society exists due to various reasons:

- Label of HIV as an incurable disease;
- Label of an HIV-positive person as an “unclean” person;
- Continuous concern and fear to be infected, which is directly related to the low level of tolerance within the adult population concerning PLHIV.
- It is the HIV-positive person himself or herself that is condemned in society as much as his or her behaviour that has resulted in the HIV infection. Thus the person is punished by creating conditions and environment for his or her social exclusion:

_Then some kind of negative view appears that the person is conducting himself improperly, has behaved improperly and at once that kind of behaviour of the person which triggers this infection or the disease itself is condemned. You get infected because you behave badly. Since you behave badly, you are bad, so I will not communicate with you, as the bad behaviour affects me as well, I’m ashamed or something worse... [social worker]_

- Fear factor is stronger than the person’s accurate knowledge:

_But there is the likelihood really, the possibility of getting infected ... and as for the information, I don’t know, I don’t think there is a lack of it ... children, without doubt, they should get acquainted with, but in general, there is a lot of information... [social pedagogue]_
There is such a case, from acquaintances; it was not HIV, but tuberculosis. Yes, there was an infection, and it seems that circle of physicians, who knows everything and the reasons, and it was not open and there was no chance of infection, that attitude, that behaviour was so disgusting that you couldn’t believe it. If you stay among teachers and hear that now that tuberculosis is spreading so quickly, and if someone like that appeared, how can you say to him in the collective? Well, certainly, you won’t be able to work there...still you will have to leave, but until you have encountered this, you don’t have such questions...but when I came across it...you just think, for God’s sake, you are simply written off, excluded. Though maybe you will

Table 11. Reasons for the Hazard Stereotype of PLHIV in Society

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<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
<th>Category</th>
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<tbody>
<tr>
<td>Fear and self-defence factors – stereotypical attitudes towards HIV/AIDS in society</td>
<td>HIV/AIDS – the label of an incurable disease; HIV/AIDS – the diseased person is “unclean”</td>
<td>Perhaps due to the fact that it is incurable… Yes, because it is incurable. Fear factor...This is the fear factor, of course... &lt;…&gt; it seems that a person like that is “unclean”, a fear that…</td>
</tr>
<tr>
<td>Concern regarding the threat to society</td>
<td>HIV/AIDS is an infectious disease and “why would one tolerate it?”</td>
<td>I think it is a stereotype, perhaps. He has behaved improperly and due to this he causes some kind of a threat to society.</td>
</tr>
<tr>
<td>Society condemns the behaviour of a person with HIV/AIDS that has caused HIV infection, not the person him or herself</td>
<td>Society’s requirements to base oneself upon common positive behavioural and moral norms</td>
<td>I think the causes of the infection are taken into account. According to the statistical data, there has been hardly any small children infected in Lithuania, only adults get infected, namely those, who use drugs, at most, or have some unsafe sexual relations...</td>
</tr>
<tr>
<td>Fear is stronger than awareness on HIV</td>
<td>But there is the likelihood really, the possibility of getting infected ... and as for the information, I don't know, I don't think there is a lack of it... children, without doubt, they should get acquainted with, but in general, there is a lot of information...</td>
<td></td>
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<tr>
<td>Fear to die that lies in the subconsciousness</td>
<td>This could even be things from the subconscious, a fear of death, we all are afraid after all...People are afraid of even thinking about it; it seems that after thinking about their infected brother or sister, it is possible to get infected... There is a certain percentage of people, who have got infected without obvious reason...</td>
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<tr>
<td>Fear to have an infection or get infected</td>
<td>Accurate information about HIV – prevention of panic and fear in society</td>
<td>...I learnt about HIV in 1996 and 13 years have passed and people’s thoughts have not changed, as they were 13 years ago and now. Very little information. If people have information how it is passed on, how you can get infected and then people are afraid. If they understand what is going on, what will be, then there will be less panic.</td>
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Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

HIV-positive persons’ insularity

HIV-positive persons’ “burdened” and “locked up” soul

<...> I have patients, who have come to me as if to a psychologist… I consult them, start psychotherapy… I have a woman, who has given birth to two children, they are healthy. These people are normal people, but their soul is very “burdened” Their soul has been locked up; they don’t want to talk about it with anybody.

Complex PLHIV lifestyle transformations

The need of HIV-positive persons to have a strong stimulus to enable themselves to change their way of life

I have one client, whose mother <...>, and father <...> … a good family. But their daughter has HIV, uses drugs. Now she has given birth to a child and does not use drugs, spends time with her child and belongs only to him. Her attitude has changed.

HIV-positive persons who have decided to lead a full life and the enabling of themselves to live a positive life

...I was <...> at a congress of HIV-positive persons <...> it was so interesting.. there was a woman from <...> who has given birth to two children, being HIV-positive, both children are healthy, she takes tablets <...> she wants to live badly, she is so positive <...> I saw her and I was thinking: “we are healthy, but people like that... Absolutely different information about life... They live each day only positively... [psychologist]

not be told directly to your face but you still will feel that attitude...I think this will not be dealt with until every third person has it... [social pedagogue]

Fear to die, get infected or be infected lying in a person’s sub-consciousness.

The research participants state unanimously that a very slow process of thought transformation has taken place in society in respect of HIV-positive persons, so the earliest accurate briefing possible of people about HIV is one of the primary important steps to the prevention of the social exclusion of PLHIV. Society’s thought transformation should be influenced by the very HIV-positive persons themselves; however, it is very hard for them because as a psychologist put it:

These people are normal people but their soul is very “burdened” Their soul has been locked up; they don’t want to talk about it with anybody. [psychologist]

HIV-positive persons, having a strong external stimulus, often are able to empower themselves to live a positive life and change their former way of living:

<...> A woman from <...>, who gave birth to two children, being HIV-positive, both children are healthy, she takes tablets <...> she wants to live badly, she is so positive <...> I saw her and I was thinking: “we are healthy, but people like that... Absolutely different information about life... They live each day only positively... [psychologist]

Is it necessary to separate HIV-positive and HIV-negative schoolchildren in the educational process? The education specialists are unanimous in maintaining a viewpoint that HIV-positive children should not be separated from HIV-negative children in the educational process and at school. However, the context is complex: society uses exceptionally negative stereotypes as a basis, and the only psychological protection is the strict observance of confidentiality in the school environment – only a few individual specialists should know about it, specialists who must be able to commit themselves to not releasing confidential information. The public disclosure of information means panic in a school’s community, even possibly condemnation, especially of the HIV-positive schoolchild or the child’s parents, if they are infected with HIV. So, information insularity is a step in preventing the social exclusion of HIV-positive children. The focus group participants made the following statements based on frequently heard experiences:

If they get to know, there is going to be panic immediately… 100 per cent. [social pedagogue]

The very child can have a kind of hostility appear, more or less like what, I’m going to get you infected? Then the whole school really will find out. [social worker]

First of all, then the parents would demand separation [of the children]... [social pedagogue]

However, there is another kind of experience that must be said about the present situation, because ignorance about it and the receiving of information from other sources i.e. outside the school environment, may cause a very strong emotional shock:
When you mentioned the case, there would be hostility. We had a case with tuberculosis and learnt our lesson. So now, if we find out about any case we inform the class as well and talk a lot in order to prevent something worse. Because there was a girl who was ill with tuberculosis. She knew it and she was treated and tests were made at school and it became clear someone talked about the results, they were leaked... then all teachers rushed to have tests, there was panic, bad panic, nobody knows why...Then we went to that class a lot, talked about it, because one more girl appeared, later on somehow those children were accepted in a tolerant way...[form tutor]

Therefore, there is a need to develop not only the tolerance of schoolchildren but also to include parents in this process, for example: the obligatory participation of parents with their children in lessons dedicated to the development of common values and information about the harmful habits and HIV. However, the data analysis has distinguished another important need of a school as a learning and educational environment concerning HIV-positive schoolchildren: to teach an HIV-positive child to adapt himself or herself to the social situation determined by the diagnosis, to take care of his or her health and protect the environment from possible infection.

It is necessary to prepare a child to live with it, just as he or she is, the way epileptics are prepared, little children are also prepared, who are ill with diabetes, he or she should be prepared himself or herself how to behave in certain cases. [nurse]

The very child himself or herself must be responsible for that insecurity near him or her. Certainly, it is an immense responsibility for a child, but that's the way it is... [psychologist]

Are there any restrictions for an HIV-positive person in selecting a profession? The research participants state that there are no specific restrictions for an HIV-positive person in choosing a profession. However, this person should deliberately enable himself or herself to protect his or her health and assume responsibility for it. And if a person knows, being HIV-positive, that he or she may get injured at work and create preconditions for other people to get infected in this environment, then he or she should consciously make up his or her mind regarding a change of their profession:

My client <...> who has given birth to children, has been working <...> at a cafe, as a waitress. Well, how do you find that <...> in my opinion, it should be restricted. <...> To work as a waitress? <...> Yes. <...> Why not, in this case? <...> I know that the HIV virus cannot stay alive at a temperature of 100ºC, but it is alive at a temperature of 56ºC. If a waitress brings salad and maybe tastes it with a spoon... nobody knows about that person's manners... but a waitress does not cook any food, she just brings it <...> here, their own attitudes should be changed, they should behave responsibly in the environment where they are, they should make up their own minds on what they should do, where they should not work... [psychologist]

Perhaps we are talking more about that person's responsibility. <...> I have a problem and I am carrying a sacrifice i.e. I undertake to protect others around me. This is my responsibility and I change my favourite job, searching for another job that I like. Besides, I don't know perhaps it is only for me, it is never like I just want to be social worker and nothing more... I know that if I were not a social worker I like this and that, perhaps I could realize myself in that sphere... To be HIV-positive and work with meat, can that be justified? You can chop that meat for yourself but not for others...[social pedagogue]

However, the specialists working in the educational sector acknowledge that the proper conditions should be created for a professional career for an HIV-positive person, just like for other people, though consultation with specialists is necessary until the selection of a profession – both with specialists who have been involved in those activities in order to find out all subtleties of that job, as well as with medical specialists, especially infectologists. Thus there is a need for a consultant from that profession for HIV-positive persons:
So there is an HIV-positive person, who has been undergoing a crisis and there is a specialist, who provides assistance and I am a consultant, paid sufficiently, who provides services to that little person...[social worker]

Despite the person's infection with HIV, the factor of having a calling to do something should not be ignored:

We as if have already directed people that they should work here or there... what about their calling? A person's right to choose? But we are not talking about that, we have already made up our mind that we allow them working here or there... We all like our favourite jobs, what about them? We are excluding them again? <...> I've got an impression that we let them work there, we let them work there, a psychologist, well alright... let's let them... [nurse]

Does the educational system possess the possibilities to expand the limits of tolerance among schoolchildren and adults concerning PLHIV? The research participants state that their environment has been in a constant dilemma regarding the acceptance of PLHIV: on one hand, a need to communicate in the same way with HIV-positive persons is understood, on the other hand – the development of positive thinking is overcome by fear, which is conditioned by the threat of death caused by HIV. However, the research participants claim that a person's status in society correlates with tolerance to that person, i.e. if an HIV-positive person is of a higher status, then the society's tolerance level is higher for him or her than for person who has a lower status. However these statements are only premises and observations, and require more thorough research and verification of particular hypotheses. The social pedagogues who participated in the group interview claim that prevention programs are prepared in schools and teachers must prepare them each year, however another question is their effectiveness, which has not been monitored by anyone. The respondents emphasize that the subject of ethics is extremely suitable for discussions on the problems of HIV. However, the pedagogues with experience indicate that the range of topics on the subject of ethics is narrow, and ethics is orientated towards general human values in general, but other specialists' efforts and motivation should be concentrated on an integrated education in order to have more effective and efficient instruction. Yet another of the primary obstacles at school is common, which is the orientation of all the educational system solely towards student achievements, leaving aside personal values, social values and social competence and the child's emotional intellect.

<...> I've had the impression that lessons and all other activities are oriented more towards student achievements rather than towards that emotional intellect. [pedagogue]

Therefore, there is a need to have a separate course about various diseases, which would increase society's social sensitivity (in both a positive and a negative sense) at school.

Informational lessons given by a health care specialist are occasional, so there is no sense in talking about their efficiency or effectiveness. One more obstacle is the large classes of schoolchildren. Material related to HIV and its various aspects should be taught to small groups of schoolchildren pursuing not only the absorption of knowledge, but an impact on the development of social competence and emotional intellect:

And if there would be a health care specialist? Well, there are a lot of classes, you won't go there to those classes during the lessons, you have to go after classes. If they have 7 lessons a day, you come and see they are fainting and they don't want to listen to anything. On the other hand, there is a way how to say it, classes are large - 28-29 schoolchildren. You should separate them, [but] how? And you cannot go to all classes, for example, you are absent from school that day, they have a special after-class meeting... if you can go there, you could go there more frequently, but you can visit one class only once a school year. You do your best, but it is just like, an introduction ...[nurse]
### Table 12. Potential Problems for PLHIV in the Lithuanian Educational System

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
<th>Category</th>
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<tbody>
<tr>
<td>HIV-positive person’s decisions determined by society’s categorical attitudes</td>
<td>Decision to not let society know about their diagnosed HIV</td>
<td>Acceptance&lt;…&gt; society dulls a person, that problem is both in school and in society, what else is there to do, just to wait, until that last day comes. He or she is not accepted anywhere, he is not needed, he/ is rejected by society... rejected. They come to a conclusion that he can live fine, if nobody knows...</td>
</tr>
<tr>
<td>Diminishing of the problem of HIV, which requires exceptionally focused attention, which is conditioned by society’s stereotypes</td>
<td>By ignoring the relevance and importance of HIV, the responsibility is transferred to others</td>
<td>An attitude… a stereotype has been shaped, moulded… an attitude… There is nobody to work with that problem...Our state, we just pretend that such a problem doesn’t really exist... nobody has to work with it, and we just wait and see what will be next?</td>
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<tr>
<td></td>
<td>Lack of time to pay attention to the problem of HIV at schools</td>
<td>And, it appears that there aren’t so many lessons to talk about it at school&lt;…&gt; but we cannot dedicate our time just to discussions about AIDS…</td>
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<tr>
<td></td>
<td>Unpreparedness to discuss HIV problems in families</td>
<td>&lt;…&gt; We are unprepared at home, we feel like we are unprepared&lt;…&gt;</td>
</tr>
<tr>
<td>Need for HIV/AIDS educational activities</td>
<td>A need for accurate information about HIV/AIDS at school</td>
<td>More information is needed&lt;…&gt;</td>
</tr>
<tr>
<td></td>
<td>A need for follow-up projects about HIV/AIDS at school</td>
<td>&lt;…&gt; more kinds of various follow-up projects...We have a new course – family psychology, as much as I have talked with the psychologist, she says: “I didn’t think that children have no idea at all! It means that children know nothing, elementary things. Not to mention HIV, even about things related to sexual intercourse.</td>
</tr>
</tbody>
</table>

The third obstacle is the competence the person delivering information in managing the room conveying the material in an understandable way, and stimulating the schoolchildren’s curiosity, interest and motivation to learn:

*I just wanted to say that not just anyone can tell just anything to just anyone at school. As there is a pedagogue, who has been born or trained to be one, there are lecturers, who have been born or trained to be ones. If the children chew you up, it’s better not to talk about topics like that. Then afterwards the trouble really is, in my opinion, bigger...* [social worker]

**What problems can arise for an HIV-positive person in the Lithuanian educational system?**

The following aspects can raise problems for an HIV-positive person in the Lithuanian educational system:

1. Categorical attitudes in society, which influence an HIV-positive person’s self-determination to inform their environment about the diagnosis;
2. Diminishing of the problem of HIV that requires particularly focused attention, which is conditioned by society’s stereotypes. This is done through ignoring the importance of the problem of HIV, whereby responsibility is transferred to others, more precisely to anyone else, and the large workloads of teachers and orientation only towards student achievements at school, which pushes HIV problems to the periphery;
3. HIV problems are exceptionally rare and may be occasionally discussed in the families of schoolchildren -

*An attitude… a stereotype has been shaped, moulded… an attitude… There is nobody to work with that problem...Our state, we just pretend that such a problem doesn’t really exist... nobody has to work with it, and we just wait and see what will be next?* [social pedagogue]

4. Information about HIV/AIDS is not conveyed systematically according to the age groups of pupils in schools. This topic has not been integrated with other subjects, which greatly impact the development and acquiring of social competences and common human values;
5. There is a lack of follow-up projects about HIV/AIDS in schools.

**Does the Lithuanian educational system create preconditions to take the needs of PLHIV into account?** The research participants are not optimistic: the group interview participants state that only a specific event and particular experience acquired through it will lead to paying attention to the problem of HIV and HIV-positive persons’ needs:

*I think that there are no proper conditions, there will be shock therapy and someone should go all the way down that path from A to Z so that they could learn a lesson and should be ready to accept a second child like that. That’s my opinion. It would be terribly hard.* [social pedagogue]

The interview participants claim that the first problem would be the ignorance of people in the school environment in how to behave with an HIV-positive schoolchild.

*Theory is one thing, but practice is another. We all understand that we should discuss it, inform others, but when we encounter it in reality, what happens then? Nobody knows how to behave. And each of us, how we would react? It is the same with epileptics, there are a number of people like that, but when he or she falls down on the street, first of all, you are confused, you don’t know, what should you do? There are a lot of people who just pass by… but this illness is one thousand years old, however AIDS - it is a new disease. And we still don’t know one thousand years later, will we also know what to hold the head or a leg.* [social worker]

There is a constant dilemma - to say or not to say it? To whom can it be said or not said? Its indecision encompasses social aspects, psychological aspects and physiological safety and morality aspects, and currently information about diagnosed HIV is one of the ways to protect ourselves from psychological pressure and social exclusion in the school environment.

**Are there any persons who initiate events related to tolerance towards HIV-positive persons in your educational institution, and what are these events like?** Events promoting the development of tolerance among children are held in schools. Specific event on HIV topics are not frequent, however, there is at least one organized during a school year. Most of the research participants say that one of the most effective forms is a competition in which teams of schoolchildren can participate. Such a form of the event encourages the team of children to learn, to deepen their knowledge, and to win on the basis of what they know:

*<...> This year there was a schoolchildren’s competition <...> on the topic of HIV <...> namely to commemorate that day [HIV/AIDS]. It was interesting, the schoolchildren really had a lot of knowledge, we were participating in a panel commission. <...> There were moments when replies were given in the blink of an eye. They were so prepared, they knew so much, I could not have answered so fast. It appears that children have information. They became interested, prepared. They most likely prepared for it. I was very surprised that schoolchildren had so much knowledge about it. <...> Yes, the rules of the competition were: this team which gave the best and most accurate replies to the questions about HIV/AIDS would win. The children had been preparing for nearly a month. There was a bibliography of sources, from which the questions were going to be asked. And the children prepared, they were motivated.* [social pedagogue]

The medical specialist in school – a nurse – states that short lectures to schoolchildren is an extremely effective method. Afterwards this information is transferred by them to others, i.e. from children to children. However, children are taught and made ready by the nurse to pass on this information, so they feel competent in the available information about HIV, while discussions within peer groups are extremely effective. The presentation of information in a game format is also suitable for schoolchildren. The integrated work of all the specialists working at school is important in preparing targeted activities, and lectures to schoolchildren about HIV. It focuses the entire school community towards the self-empowerment to learn, the appreciation of human dignity and the development of the culture of
the school organization based on the values of equality, human dignity, tolerance and goodness. It is extremely valuable when an HIV-positive person shares his or her experience with the schoolchildren - young people have real possibilities to communicate with an HIV-positive person, ask him or her questions and receive answers. It creates a natural situation to nurture tolerance and human dignity:

*It seems to me that children are more tolerant towards an HIV-positive person than his or her parents.*

I invited an HIV-positive man, who brought a film about HIV and talked about his disease, about his friends, about society and I saw that our schoolchildren looked at that man differently, and later on they shook his hand. It wasn’t horrible. [psychologist]

**Is there any medical examination for HIV before taking a child to kindergarten or school in Lithuania?**

The research participants stated unanimously that there was no special examination for an HIV-positive or HIV-negative child before taking him/her to kindergarten or to school in Lithuania. Medical specialists must undertake the protection of confidential information. If there are cases related to the child’s health status, where there is a divergence from the standardized physiological health norms, the medical specialists together with the child’s parents reach a consensus, as to whether information about the health divergence should be recorded in the child’s medical certificate or no. In this way, the child’s dignity is protected and no conditions are created for the child’s social isolation in the education institution.

*There is no separation. Now even codes have been introduced, so you can’t submit information.*

*...* If a child needs special care, a physician may get acquainted with it. *...* If there are neural divergences from the psychological side, it is not even included. If you come up against it, or suspect something, you can ask. Nothing is recorded about it in the documents, then you find out that their parents did not want to... So the physician did not write it down. [nurse]

### Attitudes and perceptions of the representatives of the educational services sector regarding the situation of PLHIV.

#### Expression of sensitiveness by educational sector specialists towards PLHIV.

After learning about PLHIV, specialists working in the educational system experience pity, but accept it as a statistical fact, as a new HIV case; however, they accept it in a universal humane sense, having no experience of coming into contact with an HIV-positive person. Pity extremely strongly correlates with the perception of HIV as a fatal illness.

#### Anxiety determined by the stereotypical attitudes of society in respect of PLHIV.

Specialists working in the educational system lack accurate and objective information about HIV / AIDS, which causes their anxiety concerning a direct encounter with PLHIV – they would not know how to react and behave or what to say in such a situation. Therefore, not only general information about HIV/AIDS is necessary but also about (both positive and negative) the experiences of PLHIV, which would be the first important step in overcoming stereotypical barriers and understanding that PLHIV are not a diagnosis but people with needs, feelings, and specific competences. On the basis of the experience of representatives of the educational system, medical specialists often create conditions for the HIV-positive person’s self-inflicted worry, leaving them without consultation, provision of information and moral support in this context. Thus there is a need for the development of the social competence and emotional intelligence of medical specialists in communicating with HIV-positive persons and delivering information about HIV to society in general, as well as information specifically related to PLHIV.

#### Need for the systematic provision and follow-up of information and on HIV / AIDS in schools.

Information provided to students in schools is short-term, general, and occasional, and lacks continuity and a systematic approach in being directed towards pupils’ age and the acquiring of new social experiences. The school com-
munity, i.e. teachers, parents, and the school administration, lacks information, and this non-awareness and the lack of essential knowledge about HIV/AIDS (of its transmission, spread, and prevention) creates conditions where preconceived negative attitudes, inadequate emotional reactions and logically unexplainable behaviour of schoolchildren, their parents or school pedagogues in the school environment are created. The campaigns, quizzes or competitions conducted as a sign of solidarity with the expression of HIV-positive persons are not enough for the development of pupils’ consciousness about HIV/AIDS as a disease as well as for the development of tolerance, benevolence and respect concerning PLHIV, because activities that are conducted in a game-style format are occasional, and preparation for them require the one-time memorizing of knowledge, but not conscious deeper learning. The provision of information must be focused not only on schoolchildren, but also on their parents and teachers.

**Systematic and continued need for social competence, emotional intelligence and universal human values of students in all age groups.** Students in all age groups require education in universal values without concentrating specifically on HIV/AIDS-related problems but on tolerance, good will, empathy, compassion, sensitiveness, friendliness and other features necessary for dignified and equal communication by presenting experience-related cases of various diseases, disabilities, chronic incurable conditions, etc., which would create the preconditions for the development and growth of students’ social competence and emotional intelligence, but not ignoring personal dignity, respect, and self-esteem. The creation of a systemic approach for this kind of development and the specific orientation towards various age groups is emphasized, because schoolchildren in different age groups react differently to events, situations and cases, and the competent insights and abilities of professionals delivering information to make a positive impact that encourages their personal development in the educational process is crucial in applying various educational strategies (group work, targeted discussions, role playing, case analyses). It is advisable to start targeted discussions about HIV/AIDS with schoolchildren at the age of 10, when schoolchildren are able to comprehend, understand and synthesize the discussed ideas, but information must be submitted understandably, however not in an oversimplified manner, by getting schoolchildren interested in and encouraging him/her to understand the importance of personal responsibility in society. While orienting itself exclusively towards student achievements, the common concept of schools does not enable the maintenance of a balance with an ethical, value-based, social and civil education, which are preconditions for shaping the tolerance of pupils not only towards those who are HIV positive, but towards all people, irrespective of their health state, sexual orientation, ethnicity or sex.

**Preconditions for social exclusion of HIV-positive children in schools.** Schools avoid recognising HIV as an existing reality in society. There are no systematic discussions held on HIV as a disease, but as a social problem and problems that are faced by PLHIV. Thus by ignoring the possibility of an HIV-positive student in school, there is a distancing of themselves from an issue that is relevant for society, an assumption can be made that if there is information about an HIV-positive student in a school or about HIV-positive parents of a student, there would be an emotional breakdown or even psychological destruction on a school wide scale, which would be expressed as a combination of panic, emotional shock, anger, anxiety and of fear, resulting in the social exclusion and hostility of and psychological and moral pressure for the HIV-positive student or a student who has HIV-positive parents. Even if the way of informing students about HIV/AIDS at school is occasional, one should avoid basing an HIV positive persons’ identity as one that is “different”, which naturally stimulates the social exclusion of an HIV-positive person at the schoolchild’s cognitive level. The concept of “different” must be replaced by the concept “human being” and the concept of an “HIV link with risk groups” must be replaced by “HIV-positive persons as a socially sensitive group”. This kind of conceptual change will also make an impact on the development of schoolchildren, pedagogues, and specialists working at school and the schoolchildren parents’ tolerance based on the creation of an appropriate atmosphere in schools.
Stereotypes existing in schools in respect of PLHIV are the reflection of public stereotypes. The exclusion of PLHIV in society and the school environment is determined by the myths entrenched in society: HIV is an incurable and terminal disease; an HIV-positive person is a representative of a risk group; a fear to get or be infected; it is not an HIV-positive person himself or herself but rather his or her behaviour that does not conform to moral norms in society, which is condemned, and an HIV-positive diagnosis is the outcome of such unacceptable behaviour. The level of intolerance in society is high, and emotions are stronger than accurate knowledge, which is why the fear factor often is stronger than rational thinking, which based on accurate knowledge about HIV / AIDS, because a person is afraid to die, get infected or be infected, which may lay the basis only for fatal end, in his or her opinion. The transformation of thinking in society towards tolerance and benevolence concerning HIV-positive persons is very slow, so the provision of accurate information about HIV starting at an early age is one of the primary steps for the prevention of the social exclusion of PLHIV.

Need to separate / not to separate HIV-positive and HIV-negative students in educational / training institutions. HIV-positive students should not be separated from HIV-negative ones in the educational/learning process neither inside nor outside the institution. However society bases their thinking on negative stereotypes, and there is only psychological protection left, which is the maintenance of confidentiality in the educational institution because the public disclosure of information about an HIV diagnosed person creates preconditions for panic within the community of the educational institution where the HIV-positive person (or the student who has HIV-positive parents) studies, resulting first of all in the condemnation of the HIV-positive student or his or her parents (particularly in those cases where the parents are HIV-positive). The concealment and secrecy of information about the HIV diagnosis is a personal choice in preventing the HIV-positive schoolchild's social exclusion, though it raises a dilemma. Therefore the education for the HIV-positive schoolchild becomes relevant so that the pupil can adapt to the social situation that has been determined by the diagnosis, and to empower him or herself to protect their personal health and the health of their environment.

Need for restrictions when HIV-positive people choose their profession. There are no specific restrictions on the selection of a profession by an HIV-positive person; however, he or she must empower himself or herself to protect his or her health and the health of his or her environment and assume responsibility for this. This means that, knowing that he or she might get injured in the work environment and thus pass on the infection to others, an HIV-positive person must make a decision regarding a change of his or her profession. However this kind of situation cannot be discussed in a categorical and cut and dry manner because a categorical approach does not integrate one's calling, preference, and freedom of choice as necessary components in choosing one's profession. So, it is important to create conditions for a professional career for HIV-positive schoolchild just like other schoolchildren; however, before the selection of a profession, consultation is mandatory with the specialists of a particular profession, medical specialists, psychologists, and social workers. It means that there is an obvious need for PLHIV for job consultations conducted by the multi-disciplinary team professionals from the target profession especially in schools.

Possibilities of the educational system to expand the limits of tolerance among students and adults in respect to PLHIV. The school environment is often in a dilemma regarding the acceptance of PLHIV: on the one hand, the need to communicate with HIV-positive people on an equal footing is well understood; on the other hand, the positive development of thought is overtaken by a fear of death due to the threat of HIV. In schools, there are prevention programmes being implemented and pedagogues are required to organize them each year; however monitoring and assessment of the effectiveness of such programmes is not carried out because all programmes are only oriented towards study achievements, leaving personality, social values and social competence as well as emotional intelligence of students in the background. One has to combine the efforts of several pedagogues and other
specialists in order to implement an integrated education; however, this requires additional time, effort and a revision of the programme content. However what is more important than any other argument in today’s schools in Lithuania is the implementation of a plan. This is why there is an imbalance in school between the bureaucratic mechanisms and the personal development of schoolchildren through integrated subjects under a focused direction which have not been yet implemented. This is the second hindrance. Therefore, there is a need to have a separate course about various diseases that would raise society’s social sensitivity at school (in both a positive and a negative sense). Information related to health issues must be provided by medical specialists, who possess accurate and greater specific knowledge and freely use the terminology, know the human anatomy and physiological processes and who are able to reply to the questions that schoolchildren have accurately and thoroughly. There is a direct link between the targeted training health issues and the lecturer’s competence on the subject. However, this competence must be integrated with social management, educational management, and audience management along with self-control competences.

Potential problems of PLHIV in the Lithuanian educational system. The problems of PLHIV in the Lithuanian educational system are caused by the following factors: the categorical nature of public attitudes, which lead an HIV-positive person to not to inform their environment about the diagnosis; ignoring of the importance of HIV-related problems and the transfer of responsibility to “others”, orientation in schools towards learning achievements, leaving HIV-related problems in the background; the non-systematic provision of information about HIV / AIDS based upon the age of the students in schools. This is a dilemma that has no one single correct solution concerning the disclosure/non-disclosure of the HIV diagnosis, which encompasses social aspects, psychological aspects, physiological safety aspects and moral aspects, but the low level of tolerance in society towards HIV-positive persons leads to that person deciding to not inform the environment, where he or she is studying, as one of the prevention strategies to protect oneself from psychological, social and moral violence in the school environment and outside of it.

Table 13. Associations in the mind of Health Care Sector Specialists concerning PLHIV

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-category</th>
<th>Interview statement</th>
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<tbody>
<tr>
<td>Emotional HIV-positive person's experiences</td>
<td>Misfortunate of the person</td>
<td>Personally for me I immediately associate it with the misfortune of that person</td>
</tr>
<tr>
<td></td>
<td>A serious illness that is difficult to treat</td>
<td>A person has serious trouble, a serious illness, which is difficult to treat&lt;...&gt;</td>
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<tr>
<td></td>
<td>Expensive treatment for the illness</td>
<td>&lt;...&gt; treatment is very expensive.</td>
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<tr>
<td></td>
<td>An incurable disease</td>
<td>&lt;...&gt; To me it is also associated with the fact that currently is an incurable disease.</td>
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<td></td>
<td>Difficult emotional experiences of an HIV-positive person</td>
<td>&lt;...&gt; it is associated with the fact that he/she is having such experiences, which are really hard to cope with.</td>
</tr>
<tr>
<td></td>
<td>Guilt experienced by an HIV-positive person</td>
<td>&lt;...&gt; I hope they feel guilt that it ended up this way, because… he/she has really experienced huge psychological stress.</td>
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<tr>
<td></td>
<td>insecurity felt by an HIV-positive person</td>
<td>&lt;...&gt; First of all, this person must feel unsafe</td>
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<td></td>
<td>HIV-positive person’s blaming of onself ‘what have I done wrong?</td>
<td>&lt;...&gt; There is always denial, guilt &lt;...&gt; when you come to terms with your trouble, most of the time you analyze where you did something wrong.</td>
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<td>Concern of an HIV-positive person due to the possible disclosure of his or her way of living to society</td>
<td>I would say that people are afraid of these three letters not because of their own health, but due to the fact that his or her lifestyle would come to light. I have to deal with family members of these people and all kinds of other people and the first thing is, even from family members is the question: my child, husband or wife is HIV-positive – how did he/she get infected with it? Well, how should I know? Perhaps I know, but it is my business and the patient’s business, but not their family members’ business. I just tell them to find it out themselves. I believe that those three letters create a stigma, because it brings attention to a person’s way of living. And the way of living, whether you want to or not</td>
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Vulnerability assessment of people living with HIV (PLHIV) in Lithuania

Need for a system of assistance for the HIV-positive person

- "Does he/she know all the information about the illness?"
  - To me, as a specialist, there is a question of whether he/she knows all the information about it, what kind of disease it is. To me, as a specialist, there is a question of whether he/she knows all the information about it, what kind of disease it is.

- Does he/she know where to turn?
  - Where to turn?

- Does he/she know what specialists can help?
  - Who can help him/her?

- Does he/she need psychological assistance to dispel the myths about HIV?
  - Maybe he/she has a lot of myths, which someone can help to get rid of in order to feel more secure and safe.

Guilt projected on an HIV-positive person

- HIV-positive person's irresponsible and risky way of living
  - This issue is a little bit more complicated, because in a way, the very person is to be blamed slightly more that someone who has cancer. A thought arises that he/she is careless in life, risking.

- HIV is a punishment for not using protection
  - In this case, I think that he is guilty that he has not taken proper measures to protect himself and he has gotten it as punishment.

Feeling of sympathy towards the HIV-positive person

- Sympathy towards an HIV-positive person
  - For me personally, there is a kind of sympathy that this has happened like this to him.

- Pity towards an HIV-positive person
  - A feeling of compassion is felt.

- Sorrow due to the understanding of the border between between life and bereavement
  - When we lose somebody, we experience sorrow.

HIV diagnosis is a reason to change one's way of living

- HIV-positive person empowers oneself to live a full life
  - I cannot look at a person with anyone else's eyes, and neither with pity. I just see him/her as an equal conversational partner, a person, who may realize himself even more so in life. To a greater extent than those, who have not been touched by this disease.

Acceptance by the HIV-positive person of the situation as a result of the diagnosis

- Reflection of HIV-person about personal self-assessment and and their psychological state
  - When people come to terms with the knowledge that they have been infected, then other things become more important to them.

- Reflection of HIV-positive person on his or her relationship with God
  - What is our relationship with God?

- Reflection of HIV-positive person on his or her relationship with other people
  - What is our relationship with others?

Perception and attitudes of specialists working in the health care sector regarding the situation of PLHIV

What comes to mind have after you have found out that a person is HIV-positive?

Medical specialists treat this extremely strong feeling towards an HIV-positive person as sympathy, which integrates compassion, mercy and sorrow understanding that the border between health and illness is very thin. The medical specialists who participated in the group interview state that an HIV-positive person must cope with the situation caused the diagnosis in the following stages:

- Reflect upon one's way of living and enable oneself to lead a full life;
- Reflect upon the relationship with oneself (their feelings and psychological state), with God and with other people;
- Understand society's stereotypes;
- Empower oneself to continuously develop one's information about HIV, because it is an incurable disease and expensive in terms of treatment expenses;
- Understand society's preconceived accusations of the HIV-positive person's unacceptable lifestyle, which has resulted in the HIV diagnosis.

I would say that people are afraid of these three letters not because of their own health, but due to the fact that his or her lifestyle would come to light. I have to deal with family members of these people and all kinds of other people and the first thing is, even from...
family members is the question: my child, husband or wife is HIV-positive – how did he/she get infected with it? Well, how should I know? Perhaps I know, but it is my business and the patient’s business, but not their family members’ business. I just tell them to find it out themselves. I believe that those three letters create a stigma, because it brings attention to a person’s way of living. And the way of living, whether you want to or not…

[ X Head of Health Sector Centre, Physician]

A number of people who participated in the interview, have stated that an HIV-positive person, after finding out the diagnosis, experiences a feeling of guilt, blaming oneself and fear regarding the disclosure of his or her way of living to society. This is why an HIV-positive person must live in silence about his or her health situation, which creates preconditions for a life under continuous emotional stress and anxiety.

The medical specialists said that an HIV-positive person’s situation created an association in their mind with the need of PLHIV for assistance, when answers are necessary to questions such as the following:

“Does he/she know all the information about the illness?” Does he/she know where to turn to? Does he/she know what specialists may help? Does he/she need psychological assistance to dispel the myths about HIV?” [Manager of Z Projects Office for Baltic States Projects Division, sociologist/ social worker]

What is the attitude of medical specialists towards PLHIV? A physician working in a penitentiary states that society and the very attitude of medical specialists toward HIV-positive persons has changed little since 1989: When physicians had to encounter the first patients, they used to experience a huge emotional shock, fear, and concern due to a lack of knowledge on the disease. Later on, after a minimal amount of information appeared, the hardest thing for physicians was to let a patient know about the fatal end of AIDS, because there was no medication, the scope of tests was narrow and etc.

However now in a time where there is sufficient information and medical staff are taught about HIV, the same attitudes are still prevalent, which are often win out over precise information that is available about HIV. This fact is substantiated by the group participants’ stories about specific cases, where a physician turned pale and could not continue standing after he found out that his examined patient was HIV-positive, while in another case a physician decided he needed other instruments and went out without coming back to continue the patient’s examination. Medical specialists most frequently experience stress encountering an HIV-positive person, so even in those cases, where work safety is observed and information is precise, there is a need to talk to colleagues or director about encounters with an HIV-positive person:

I’ll give you one example. We have one person, HIV-positive today and when he comes to the laboratory, he tells that: “I’m HIV-positive”. A paramedic takes blood, everything seems to be all right, there are disposable tools, and etc. What does she do? She comes to me and says: “Today an HIV-positive person has visited me,” she looks at me to see how I will react. I don’t pay any attention. She says: “But I used all protective means”. The thing is that she understands everything, but there is fear and she comes to say it. She does not say that there has been this and this patient, as there are a lot of people, who are ill with various diseases, but she had inform me about this one. [Health Centre Deputy Director for Care, nurse]

One of the group participants has stated that society, and especially medical staff, cannot break free of stereotypes, i.e. various labels are stuck on HIV-positive persons according to their way of living, and this is the first reaction when you meet an HIV-positive person face-to-face, it is only later that you experience compassion.

It is said: “I’m HIV-positive”. OK… then the first thought is; who are you? There are three ways of it spreading. If it’s a beautiful woman – then she’s a sex worker; if it’s a handsome man – perhaps sexual relations with men, if it’s a person, whose teeth are rotten and whose shoes smell - then it’s a drug-addict. That’s all. Each of us only
knows that, in this way we start guessing about the way of infection. [a physician-infectologist working at a penitentiary]

However, physicians agree unanimously that each time you need to let a patient know about the diagnosed HIV, they experience a large amount of stress. However, the very patient often focuses his attention not towards HIV, but to adjacent diseases, which cause many complications in his life and/or at work, cause negative emotions and tension. For example HIV-positive persons have to deal with pain due to thrombophlebit. Physicians who encounter HIV-positive persons state that HIV-positive persons have a considerable need to talk thing out and be listened to and communicate, so a family physician who could perform additional roles beside his main one as a physician is of particular importance to them, for example as a psycho-therapist, consultant, and/or information provider.

What problems can HIV-positive persons face in case they need medical aid? An essential problem for HIV-positive persons is access to health care services, because HIV-positive persons don’t have social guarantees. Though specific laws have been adopted, they are ineffective. Therefore, in absence of a regulated system, medical aid to HIV-positive persons is rendered based upon a physician’s goodwill. This is why medical staff state that regulations are needed in the health care system so institutions and specialists would not duplicate their activities, and that the hierarchy should be regulated within the context of working with HIV-positive persons so it would be clear who is responsible for what and to whom one is formally accountable. Physicians are often poorly informed about existing laws and official documents related to the health safety of an HIV-positive person, so an HIV-positive person must take the initiative to arrange social guarantees, while persons coming back from penitentiaries experience emotional tension, because physicians have stereotypical attitudes that an HIV-positive person coming back from penitentiaries are not socially insured, though he is in fact insured.

Not to mention prisons, because they are insured by the state and there are no problems with them. All of them are examined properly, funds are allocated for that. And we end up with such a strange situation – we have that person in prison, we follow him, observe him, treat him and as soon as he is released, he is thrown out between heaven and earth. He goes out with all medical documentation from us with an order to go to his district physician that is treating him. The physician says: “you aren’t socially insured <…> who can accept you in a polyclinic with such a problem? [a physician-infectologist working at a penitentiary]

An HIV-positive person must also assume responsibility for his or her health safety, however often HIV-positive persons are passive, so urging, encouragement, and assistance is necessary them. In these kinds of situations a nurse and a social worker can and most often provide assistance.

If there is diabetes, there is a registry, I have diabetes and that institution transfers [this information] automatically to the State Patients’ Fund that we have such a person. The situation is different with HIV infection. He has to do it himself. These are specific people. I’m not referring to those, who work, who are of another category, but 87 per cent are injective drug users, who don’t care at all. You should take them by the hand, take them, do it, deliver them to the physician – this physician is going to examine you, this one will take care of you... or a nurse, anyone else – it doesn’t matter who [deputy director for medicine at a health centre, physician]

The medical staff have pre-conceived stigmas about HIV-positive persons, and their behaviour with HIV-positive persons clearly show this. For example, they try to check out the patient from the hospital as soon as possible, irrespective of a person’s state of health:

Yes, there was. Then she was put in the hospital. Oh, no – she was discharged the next day. It means she gave birth in the morning and was discharged in the evening so that woman wouldn’t hang around. Because “imagine, in the delivery room where we are.” So what if it’s the delivery room? “But she was bleeding”. Yes, she was.
So what? Was she the first/last? [physician and venereologist of skin and venereal diseases dispensary]

It is as if an HIV-positive person is a diagnosis at a health care centre, and not a human being with a specific disease:

You bring a patient to the same delivery division and say that this woman is HIV-positive. At the very moment everyone is against her with every inch of their being. If you say she is infected with hepatitis C – there's no reaction. Absolutely no reaction. Though, I would say, that [hepatitis] C is even more terrible than HIV. And it is far more terrible. But there's no reaction. I say it is society's attitude, an opinion that has formed about this disease. I haven't the slightest idea, how to break it. [physician and venereologist of skin and venereal diseases dispensary]

If an HIV-positive person has a question or needs assistance – where should he/she turn to? Is there any system which would create the conditions for a person to feel safe?

The medical specialists state that persons may find information about HIV on internet portals and special web-sites. However, information on the internet may have a negative effect on an HIV-positive person especially at the initial stage, when he/she finds out about the diagnosis, undergoes considerable stress and other kinds of intense feelings and emotions. A person may need the assistance of a psychiatrist. A consultation with a professional psychologist is especially necessary for HIV-positive persons, because HIV-positive persons are closed, and don't want to talk about their situation Interaction with psychologists is complex for HIV-positive persons: After a person comes to a psychologist, he/she needs to identify and name his or her problem precisely, which is a hindrance for an HIV-positive person to talk about his or her situation. There is a need for a psychologist's objective consultation so an HIV-positive person can have the opportunity to have access to consultations according to their needs.

As for psychological help, as such, I would say, it is needed, just as any other patient [needs it]. But again there's the same problem – you go to a psychologist, and he asks you to tell what kind of problem you have. And the person simply does not want to name it in this case, if he is from a higher societal level, not a drug-addict...drug-addicts do not those kinds of services... They need a dose and that's it. They can do without naming any problems. But it is more complicated for a person from a higher societal level at the psychologist's office. The psychologist tries to find out why you have come to him, where the problem is. That person understands this, beats around the bush and says nothing. Later on he goes out dissatisfied: What do I need that psychologist of yours for... We have been talking for two hours, and I left in an even worse mood than I came in with. It means that, once again there is an aspect particular to this situation, perhaps we don't have this kind of consulting institution in Lithuania, like there are abroad. When a person comes to talk and you say anything you want , it doesn't matter, whether you are HIV-positive or HIV-negative... [chief specialist of Y Centre's Information and Analysis Division and physician; physician and infectologist working in a penitentiary]

How is an HIV-positive person's confidentiality protected? The research participants state that the existing legal framework of Lithuania safeguards confidentiality for HIV-positive persons. However, the medical specialists claim that there is a gap between formal obligations to observe confidentiality and the actual observance of this principle in the medical community in practice. For example, the accessibility of a patient's health records creates real preconditions for a breach of confidentiality and anonymity principles concerning the HIV-positive person.

Yes. This is a problem at institutions. <...> There is a personal health record, and a hospital treatment record, which are accessible to everyone. In the true sense of the word. The problem is that I have encountered it several times where marks are put on the cover or on the first page of a person's health record. Green – everyone at the health centre knows that is HIV. Yellow <...> that's a matter of agreement. <...> Sometimes it is written. So now, any person, who has taken this person's health record, let's say, a nurse or an employee from the registry ... the surname, name, personal ID No., and address
are there and plus all of these other similar marks. So here you are – the entire file. And what's more god forbid,, if you see that it is your neighbour, or it's your acquaintance and hey, look, the figures that are written there ...[/manager of Z Projects Office for Baltic States Projects Division, and sociologist/ social worker]

The medical staff state that specific entries about HIV in a person's health record create clear conditions for this person's social exclusion, just as a physician's poor competence in the field of HIV / AIDS does.

**Provision of medication to HIV-positive persons: What is this system like? Are they accessible to HIV-positive persons? Are there any priority groups for purchasing medication?** The medical staff states that antiretroviral treatment is free of charge in Lithuania; however, a person must treat associated diseases from his or her own financial resources. Only HIV-positive pregnant women are assigned to priority groups, who can then get treatment. There is a need for HIV-positive persons themselves to assume responsibility for their health, and take the medication carefully and systematically without missing a single dose.

**Which HIV prevention programs that are being implemented are effective?** The participants of the focus groups name methadone and psychosocial programs as effective programmes. The arguments for the effectiveness of the methadone program are the following:

- The number of injections is decreasing and the need for other drugs is minimal;
- The number of crimes where one is under the influence is decreasing;
- The programme's integration with psycho-social assistance and case management, making an impact on the HIV-positive person's behaviour.
- The HIV-positive persons have an opportunity to obtain assistance and consultations from psychologists and social workers in psycho-social assistance programmes. These aforementioned specialists are mediators that help HIV-positive persons to integrate into society, look for work and etc. The research participants have also mentioned the limitations of various programs that are being implemented:
  - The local impact of the programme concentrated only on a specific group of people,
  - The appearance of unforeseen problems in the program,
  - Specific occasional assistance for HIV-positive persons within the limitations of the programmes;
  - The realization of programmes in places of detention,
  - The irregular character of programmes, and lack of continuity of programmes.

**What would be effective in order to in essence create a positive shift so that HIV-positive persons’ problems would change and would become more understandable to society?** The research participants name the following factors, that would change the attitude in a positive sense concerning HIV-positive persons:

- A greater degree of tolerance for HIV-positive persons in the medical workers’ community and society;
- The systematic and professional-quality level of informing and educating various age groups about HIV / AIDS;
- The growth of knowledge and competence in the sphere of HIV / AIDS by training physicians and other medical staff, social workers, nurses and pedagogues;
- The sensitivity and empathy of medical workers towards HIV-positive persons.
Attitudes and perceptions of representatives of the health care sector regarding the situation of PLHIV.

Expression of sensitivity of health care sector specialists towards PLHIV. Health care specialists understand the complexity of the social situation of an HIV-positive person which has been created by the diagnosis: in a societal context, the HIV-positive diagnosis is a "punishment" intended to "punish" the HIV-positive person; therefore, he or she must repent and society does not want to forgive him or her for this. This kind of situation is a dominant stereotype in society, which is understood by the HIV-positive person himself or herself. Therefore they must cope with their emotions, reflect upon their life in relation to themselves, to others and to God, understand and come to a realisation about society’s stereotypes and his or her own perceptions about these stereotypes and the opportunities to adapt to these stereotypes in an evolutionary manner and find the strength to empower themselves to the safety of their own health and systematic self-care, the continuous development of knowledge about their disease, communication with their environment and specialists and a change of their way of living if it was related to drugs or alcohol consumption, and a change of their attitude towards sexual relations, reflecting upon the concepts of their partners' change and self-protection, and partner’s safety, which one has to deal with in coming to terms with the life that has been created by the HIV diagnosis. The medical staff understand an HIV-positive person's decision not to notify their environment about the diagnosis, because it is a personal strategy to protect oneself psychologically and morally, however, they do not justify such a decision, because this strategy of "saying nothing" is always a dilemma decision in terms of ethics, morality and health safety. Therefore, in this context, the essential questions which an HIV-positive person needs to be helped to get answers for are related to full and objective information about HIV and opportunities concerning the provision of this assistance (especially psychological assistance).

Stereotypical attitudes among medical specialists concerning PLHIV. Medical workers are taught about HIV, but stereotypical attitudes are often more influential than accurate information on HIV. Having encountered an HIV-positive person, physicians or care specialists still often act unprofessionally by humiliating the human dignity of the HIV-positive person and the professional dignity of the professional medical community. The first reaction, which is based on the "labels" medical specialists use for PLHIV, are stereotypes that identify PLHIV with risk groups that have already become a stigma due to their lifestyle and potential for becoming infected with HIV. Only later do the humane feelings of medical workers, such as: sensitivity, compassion, and sympathy, "switch on" (or do not "switch on").

Professional stress experienced by the physician when providing information about the patient or receiving information from the patient about the diagnosis of HIV. The stress and emotional discomfort experienced by the physician before, during and after informing the patient about the HIV diagnosis shows that the physician simultaneously experiences multiple kinds of professional stress in the work environment which are difficult to deal with emotionally and psychologically. However in this situation the physician is the person providing information. And when the opposite case occurs, when one is unexpectedly caught unprepared by an HIV-positive patient who himself states the fact of HIV infection, the physician experiences stress caused by stereotypes in society. Consequently, the physician faces a dilemma as:

(a) a medical worker as a professional he is the “master” of the situation in informing the HIV-positive person, catching the patient unexpectedly and providing at least in the worst case scenario partial moral or psychological support to the HIV-positive person.

(b) a medical worker as a human being, where his professional role is secondary or his role as a professional is restricted within the background of stress that is experienced, or emotional tension. In this kind of situation the physician represents his being, expresses emotions as a human being, a member of society that is influenced by the stereotypes. He then he protects himself from the patient with
inadequate behaviour, which the HIV-positive person takes sensitively, because he
expects professionalism, competence and the execution of professional obligations
towards the patient both from the physician and medical staff in a broader sense.

In this context, a need has become apparent for the development of multi-faceted
competence, communication, situational management and the prevention and
management of issues pertaining to conflict, self-control, and consultations, which
integrate more detailed social-psychological aspects.

**Potential problems faced by PLHIV in cases when needing medical help.** The main
problem for PLHIV is access to health care services because PLHIV do not have social
guarantees, even though specific laws which are ineffective, have been passed.
When there is no system for a regulated legal basis in terms of tangible results,
assistance provided to PLHIV is often based on a physician’s goodwill. Therefore,
regulations are necessary in the health care system so that activities and functions
of institutions and specialists would not overlap and that there would be a clear
hierarchy based on responsibilities and accountability in working with PLHIV. The
poor knowledge of physicians about the existing laws and official documents re-
lated to the health safety of HIV-positive persons has lead to a situation where the
HIV-positive person himself or herself should take initiatives to become aware and
arrange his or her own social guarantees. Considerable emotional discomfort is felt
by persons who have returned back from penitentiaries, because the physicians
have prevailing stereotypical attitudes that an HIV-positive person, returning from a
penitentiary is not socially insured, though he is in fact insured. Then accessibility to
health care services understandably is “limited” to that person and such a situation
empowers the person to take the initiative and fight for his health care quality, the
restrictions of which have been caused by the diagnosis of HIV and an environment
of societal unacceptance, a stereotype of the “ex-convict”.

**Obstacles for the functioning of a comprehensive PLHIV support system.** An
effective PLHIV support system based on continuity, prolongment and systematic
organisation does not exist. The statement of the public at large and individual
specialists that there is a lot of information on internet portals is irrational. Unprofes-
sional information may be found not only on internet portals but also in magazines
and newspapers. However, there is a need for an HIV-positive person to receive
professional, reliable, and accurate information provided in an understandable way.
In other words, the person must know who the (a) provider(s) of such information
is, what professional spheres they represent, and through what communication
channels they can be approached. One cannot deny the importance and signifi-
cance of face-to-face communication and interaction for the HIV-positive person,
especially at the initial stage when they find out about the HIV diagnosis. During
this stage an HIV-positive person can form a distorted picture of the situation by
only reading information that is on internet portals, which may cause additional
psychological stress, psychological problems or a fatal end by not controlling one's
emotions and not being able to rationally adopt a decision to empower oneself to
take for responsibility, first of all, for the quality of one's own health and life. This is
why consultation with a psychologist and family physician is important, however
consultation is relevant to the HIV-positive person according to his or her own
needs. The psychologist’s competence must be specialised in this context – in
communicating with an HIV-positive person, it cannot be based on conventional
consulting techniques, because this limits the person’s openness, an experiences
discomfort and considers the psychologist’s consultation useless.

**Possibilities of maintaining confidentiality in the health care sector.** The legal
base created in Lithuania guarantees the confidentiality of PLHIV; however, there
might be a gap between formal obligations to keep confidentiality and the actual
observance of this principle in practice in the medical community. Specific entries in
an HIV-positive person's health records create clear preconditions for that person's
social exclusion.
Limitations in the provision of medicine to HIV-positive persons. In Lithuania, antiretroviral treatment is free of charge, but a person must have associated diseases treated with his or her own financial sources.

Limitations of the HIV prevention programmes being implemented. The obstacles in the programmes being implemented could be linked with the effectiveness’s local confinement along with the irregular character of programmes only oriented towards a specific group of people in the absence of continuity and being prolonged; unforeseen problems arising during the implementation of the programme are eliminated at a slow pace; assistance provided to PLHIV within the framework of the programmes is one-off in character and usually piecemeal; the majority of programmes are implemented only in penitentiaries.

Factors having a positive impact on increasing the level of tolerance concerning PLHIV in society and medical community are the following the need for medical workers to develop social and communication competences, to deepen their knowledge on HIV / AIDS issues, to expand their emotional intelligence; to promote and ensure the systematic provision of information and education on HIV / AIDS and professionalism for different groups of people based on their age, various institutions and the professional medical community by involving experts representing the fields of medicine, public health, psychology, social work and care to carry out educational instruction.
Perception and Attitudes of the Representatives of the Labour Market (Employers) and the Non-Governmental Sector about HIV and PLHIV

Society’s attitude toward people living with HIV or AIDS. The following dimensions have been mentioned in the employers’ conversations about their attitude toward HIV-positive persons

A global dimension, in which a position is held that society is not protected from various diseases and by changing society’s activeness, way of living, then the nature of diseases and their modifications also change. This is why the primary tool for preventing societal panic is informing the members of society (from the young to the old) in an understandable and basic medical language, and the taking of responsibility by society regarding HIV prevention and a consciousness development, knowing that “everything is close by”.

Everything is close by. He must know how to escape this disease, but also understand that these are people. Today he can ignore, condemn, and rip on those people, but tomorrow he can find himself there. A lack of information and explanation...

(2) A passive, neutral or retreating dimension, where each HIV-positive person is treated as a statistical fact showing how many people are ill with certain diseases or whether they have been infected and absence of consciousness, adhering to a position that HIV is “far away from me”.

These are pure statistics. You just see, if you don’t encounter with such people, they just are... Are they ill with tuberculosis or any other disease...Hepatitis C is no less dangerous of a thing...No less. An ordinary statistical unit. Yes, it’s an ordinary statistical unit.

(3) A dimension of society’s health safety, which covers specific questions about HIV/AIDS control and monitoring opportunities, and a degree of danger for the environment and the HIV-positive person him or herself.

(4) A civic pride dimension, which has two poles - an HIV-positive person who is a member/citizen of society and HIV-positive persons who live and work in a civic society. It means that HIV-positive persons have to assume responsibility for their own health safety and their environment, and society must also assume its responsibility for the implementation of HIV prevention measures. However, society avoids assuming its responsibility and projects the blame directly on HIV-positive persons, thus their categorical position and the phenomenon of punishment are essential factors created preconditions for HIV-positive persons to be socially excluded. This kind of categoricalness by society causes HIV-positive persons to hide their health status, which leads society to become less safe and more sensitized.

(5) A communication dimension, which concentrates upon informing others about HIV – information is provided to society by medical staff about strategies and ways to avoid HIV, ways of its transmission, spread and basic physiological processes when one is ill with it. Informing others is necessary not only general, but also specific i.e. at work, etc. Awareness creates conditions for the development of the degree of people’s tolerance, and awareness in maintaining one’s health and preventing stereotypes in society. Society’s lack of awareness and knowledge about HIV leads to an imbalance between tolerance and goodwill and categoricalness and intolerance.

I know, if I said to the team that you, communicate here, this man is good, but he is slightly ill with AIDS. Either everyone would start running away from work or… It would be a problem, because there is no such information. What is mysterious is very terrible. Here it is terrible and dangerous – an absolute limitation and he would
rather agree after a referendum has been announced. Isn’t compulsory euthanasia needed? He would go to vote in favour of it. It depends upon the person. The biggest problem is ignorance, what it is. [manager of private limited liability company T and businessman]

<...> in real life <...> to break through a wall <...> After a year or two of working, people would see that they have not been infected after, breathing the same air <...> society is not sufficiently enlightened. They are not only in the dark, but do not have enough goodwill. [manager of private limited liability company R and businessman]

(6) The labelling and stereotype dimension reveals that society’s lack of knowledge causes the identification of risk groups as a social phenomenon, a lifestyle, and with HIV, which is a disease with specific symptoms, treatment needs, health safety, and various types and levels of disease prevention.

There is a problem in our society that an HIV-positive person is identified with irresponsibility, the use of drugs and etc. Maybe once we should make a difference between them. Dependency is one social phenomenon. HIV is a disease. [head of NGO Z]

The identification of key groups at risk with HIV causes the exclusion of HIV-positive persons not only in specific work or life environments, but also in the labour market in a general sense.

Regardless of how it is, our society is inclined to look for guilt. <...> I'm inclined to think that it's doubtful where people think <...> poor creature, ill with HIV, perhaps he had a blood transfusion.” Somehow I think that typically think “Yes. He has been living in the wrong way. He is to blame and it has consequences.”[ scientist of centre Y at institute X]

They have the mark of guilt or stigma. Only due to this that he is rejected he is a leper. He had sexual intercourse, was careless, in every way, to put it bluntly. [ scientist of centre X]

Society does not forgive a mistake and punishes without giving a chance to a person to correct the mistake.

But then it is possible the whole time for a person to correct a mistake. He has been infected, he is changing his viewpoints, his life, he has changed. Why we should look at him as a leper, if he is studying, learning, is looking knowledge, becoming a positive member of society, he’s the same as everyone else. [director of cafe D]

(7) An educational dimension, which means society’s need for knowledge, education and development concerning health safety issues in order to protect oneself and one's environment from possible illness and take preventive measures as soon as possible in the case of illness/marginal health situation on an individual and societal level. This dimension also encompasses basic preparation studies for specialists and post-graduate studies, where people deepen their competences in specific areas. However, there is a dilemma regarding (non)-mandatory training on HIV: if HIV/AIDS issues have been included and studied in the main programme for studies, then someone who is studying, a future specialist naturally must learn, because formal verifications and assessments exist in the learning system, which are related with the person’s motivation to study in order to know and be competent.

All of us studied and we know very well that even this, what really was a very good program and good teachers...at that age when you’re studying, you don’t always learn everything. At least I studied what I was really interested in. I would think that post-graduate training would be of much higher value. Namely when one has already started working and really knows, what kind of work it is, when one feels one needs this knowledge. [scientist at centre Y at institute X]

Post-graduate studies are not mandatory, which is why a person’s learning or studying motivation may be low, while the very studying process is more superficial than it is deep.
If post-graduate studies were not mandatory, it would be even less of a motivational factor to study. Nothing is going to force a person to study until it has become relevant to him, like for you, you didn’t need those notes until you lacked milk for the fruit. There is no difference, whether it would be in the programme, or it would be after graduation… but if there would be something in the programme that he would have to account for, there’s a chance that he still remembers something. As for post-graduate [studies], I don’t know, it doesn’t interest me… [manager of private limited liability company T and businessman]

The attitude towards HIV-positive persons can change dramatically only through education, which is why education and studying at school is necessary, because it is very hard to change an adult’s attitude and viewpoints.

We look at adults, people that have a formed character, it is needed first of all at school. It is very hard and impossible to change adults’ viewpoints, if he doesn’t want to change it himself. You can enlighten him as much as want. I think that the biggest focus should be concentrated on secondary schools, talk about the fact that there are others that are even more intolerant… I think this is a defensive reaction. [representative of NGO W]

The situation of HIV-positive persons in the labour market. The employers that participated in the focus group discussions, don’t deny that stereotypical obstacles exist in the labour market concerning HIV-positive persons:

By employing a person a priority is given not to the person’s competences, but to the person’s diagnosis, especially with an HIV diagnosis – a person’s admittance to being ill is a direct obstacle to receiving a job. When there is no financial benefit for an employer to employ an HIV-positive person and seeking other employees’ psychological comfort, an HIV-positive person is not going to be employed, while the “healthy” person is.

Two people, I’m an employer. There are no emotions, sympathy, antipathy. Certainly, I am going to select an HIV-negative person. He has lower risk of illness, if the team finds out... Everything is going to be better with a person who is healthy. If I don’t see some benefits or financial advantages by employing such a person. [manager of private limited liability company R and businessman]

(2) Emotions of fear, concern and insecurity are stronger than available knowledge and rational thinking, when a person openly speaks about their HIV diagnosis, however the outcomes are often not favourable for the HIV-positive person.

Why did I think like that? My son has been working as a social worker with drug addicts. Not long ago. He comes one day and says: “What are the ways of getting infected”? He says: “one drug-addict gave me his hand, and I shook it...” “So what” I said. “What, you have wounds there, or does he?” He says: ”My colleagues chewed me out. I have enough information about the ways it spreads, but my first reaction was... like my mother’s. I suddenly started going through all of my shelves and information I had, until the voice of reason stopped me, still I panicked a bit. I started thinking that maybe I don’t know anything, that it was my son. Therefore I say, one thing is when we make decisions, but does the voice of reason determine anything in such a situation? Can’t emotions cause it so I just can just live simpler. Emotions cause it. [scientist of centre Y at institute X]

(3) Employers’ dilemmas regarding the person’s health examination by including HIV testing, because a person’s examination regarding HIV is not mandatory. Then the person’s employment in a specific activities area would grant psychological and moral security for the employer. If the employers knew that an HIV-positive person has been employed, but that he can work in this specific area according to a list of areas/professions, they could explain to other employees with argumentation as to why the HIV-positive person has been employed, or on the basis of the list in case of contraindications, the employer would have an objective argument as to why the HIV-positive person has not been employed.

If there are areas, where a person works… there is a medical examination. HIV [testing] is not mandatory. Not everywhere. Again this question – mandatory. I have encountered
it with hepatitis and HIV in my work. My working area is the food industry, food production. I ask institutions, which are responsible for that, specifically with the food industry, with official letters... HIV, hepatitis, everything I have mentioned. No, these are not contraindications, he can work in that area. There is a health examination in each job and there is a profession written there. I think a medical worker should check that it would correspond to the specified profession. In the end they write that they can work. If I get a physician's note like that, I understand that I can employ such a person. [director of cafe D]

(4) A need for employers to develop competence in HIV and self-control issues, because it is directly related to social, psychological and physiological questions pertaining to the safety of employee health, because knowledge will be active prevention from stereotypes that exist, and will be concentrated not upon a person's diagnosis, but on the available competence. An ability to control oneself will not create conditions for emotions to take first place, but rather find rational and logical arguments for tolerance, goodwill and equality in the working environment concerning HIV-positive persons.

(5) A need for an HIV-positive person to empower oneself to protect his or her health in their work environment and in extreme cases, when there is a chance of coming into contact with blood, an HIV-positive person must be able to handle the situation himself or herself, protecting their environment or knowing protection and situational management methods, so when there is no option to handle the situation himself or herself, the person could give directions as to what ways would be safest to solve the situation that has arisen.

(6) A need for an HIV-positive person to empower himself or herself to inform his or her employer about their HIV diagnosis by consciously understanding that the employer's knowledge is a strength and the first step in the prevention of social exclusion.

(7) A need for a change of the legal framework related to the employment of HIV-positive persons because employers are interested in applied tax benefits on a national scale by employing HIV-positive persons.

(8) A need for HIV-positive persons themselves to take initiatives in the labour market and become employers themselves.

We have been analyzing everything in a very one-sided manner. In other words, how an employer looks at them. The employer is just like that very person. Why haven't they been doing anything? One day you can be an employer, the next day you can be a hired employee. Life changes. They gather into their organizations, they get ideas, but money is needed to implement them. <...> Don't look only at the employers, but at their responsibility to become employers. [manager of private limited liability company T and businessman]

(9) A need for NGO initiatives for training HIV-positive persons for the labour market and the distribution of information in work environments in order that HIV-positive persons, first of all, would be able to step through a psychological barrier and assume responsibility for themselves and their environment in the workplace. This is inseparable from NGO initiatives to disseminate information in various work environments. This is an effective step in preventing discrimination of HIV-positive persons in work environments.

If there was sufficient information about you for the environment, there would not be such a shock, you could accept a person naturally. When I started to talk with my work colleagues, then this one person, who the whole staff knows that he is ill... it doesn't matter. There are birthdays, kisses, congratulations, nobody sticks out and nobody really discriminates. [Director of Cafe D]

(10) A need for society and NGO initiatives regarding the development of social advertisement on HIV issues as an effective prevention measure regarding the social exclusion and/or social discrimination of PLHIV.
Possibilities of maintaining confidentiality in the labour market.

HIV-positive persons are not inclined to discuss their health state openly, or talk about their diagnosis with colleagues or employers in their working environment, because they are afraid of social exclusion and additional psychological tension. However, maintaining confidentiality is a very sensitive and problematic in Lithuania, so those, who have a high social status and have financial opportunities, allocate their time for HIV treatment outside Lithuania. This is one of the ways for an HIV-positive person to protect his or her privacy. However, for those who don’t have such opportunities, there is only one option – to live with the psychological, moral and physiological situation caused by the diagnosis and hide his or her diagnosis from their environment.

Opportunities for an HIV-positive person to upgrade their professional qualifications in the labour market.

In the opinion of employers and NGOs, HIV-positive persons must not be restricted in their profession selection, however there is a need to define clear criteria regarding HIV-positive persons’ profession selection and opportunities to work in specific professional spheres, because the availability of formal criteria is an objective solution for the prevention of HIV-positive persons’ social exclusion prevention in the context of pursuing a professional career.

If he really can work, if there is no contact with blood, then I think he can work, but if there are any contraindications, then he shouldn't do that job. Then he should change his profession. In this case, it is impossible to avoid discrimination, because you must define criteria of what job or area he can express himself in. Why can't he express himself in an area that is not forbidden for him? He can express himself in any professional area. If the laws don't regulate it and forbid, then why should he be directed to some corridor? He is free, just as free [director of cafe D]

An HIV-positive person’s unambiguously negative strategy is to associate his or her problems only to his or her health situation that has been caused by the HIV diagnosis because such a position does not raise respect for an HIV-positive person, but humiliates his or her own dignity in the employer’s eyes. It means that the HIV diagnosis should not become a person’s career “banner”, but a person’s education. Having professional qualifications and competence must be the essence in seeking a career. The employers do not deny that it is more complicated for an HIV-positive person to seek a career, however everything is possible, one only needs to work and prove responsibility, loyalty and competence with their work.

No, but we are talking about a career, he is an ordinary worker today, tomorrow he wants to, if he works well, responsible, tomorrow he can be a warehouse supervisor, later on the head of any division, why not? It depends upon the personality, if he studies; if he improves ... he will achieve... But if he wants to achieve something by saying I’m ill and I’m discriminated against, then I’m not going to respect that kind of person... These are unrelated things...[head of private limited liability company R and businessman]

It is very easy to formulate. Is it more difficult to make a career for an HIV-positive person? More difficult. Without doubt. Is it impossible? It is possible. But HIV must not become his career banner...I’ve had such an analogy to seek career with equal opportunities for men and women... Certainly, if to compare an HIV-positive person and a woman, then it is easier for a woman. If a woman is HIV-positive? Then is unreal... It depends in what sphere... Women have advantages in some spheres...

[Manager of Private Limited Liability Company T; a businessman]

Preconditions for accessibility of PLHIV to health care and social services.

During the discussion of the focus group, the following aspects regarding the accessibility of health care and social services to HIV-positive persons were distinguished:
(1) the need for an amendment of the laws related to the status of HIV-positive persons in the social and health care sectors, because at the moment according to current laws, it is contraindicated for HIV-positive persons to be treated at inpatient clinics, as an HIV diagnosis denotes an “automatic” criminal responsibility and is an obstacle in using care and treatment services.

(2) the need for NGO activities in enlightening society about HIV / AIDS by presenting positive and negative experiences, the spread of HIV and other specific aspects, informing others about prevention in a systematic manner and etc. They should not be not piecemeal activities, but work that is consistent and systematic. NGOs are the most effective, because people work in these organizations that are not looking for profit, but to help specific groups solve issues relevant to them.

(3) NGO initiatives to co-operate with various organizations and entities, where NGO would perform the role as an initator of change and other activities. What would be relevant in this context would be meetings with employers, presenting HIV in various contexts, showing various sides, talking about the different experiences of HIV-positive persons. Also important would be NGO meetings and discussions with HIV-positive persons, empowering them to take charge their own health safety and the health safety of their environment,’ and the responsibility for their way of living and its quality, as well as taking the initiative and overcoming psychological barriers that they possess.

(4) the need for the expedient and meaningful use of targeted funds, so it is important for NGOs to work on the principle of a public institution, and initiate NGO coordination council meetings, which would control the use of targeted funds and, in this way would pursue the ensurance of transparency on the usage of funds and carry out effective control and monitoring.

**Attitudes and perceptions of the representatives of the labour market and the non-governmental sector regarding the situation of PLHIV**

The employers’ perceptions about the status of HIV-positive persons in society is reflected by seven dimensions representing society’s attitudes:

- The global dimension emphasizing a wave of various diseases in society due to a change in the lifestyle of society, which is why the prevention of panic is the informing of all age groups in an understandable language and society’s assuming of its responsibility regarding HIV prevention and not pushing responsibility off onto others, but empowering oneself to take responsibility for one’s own health safety and the health safety of one’s environment and the fostering of life quality.

- The passive/neutral dimension, where each HIV-positive person is treated as a statistical fact, retreating from the taking of responsibility for prevention, disassociating oneself emotionally from HIV-positive persons’ problems and ignoring the fact that an HIV-positive person is a member of society, where everyone is living i.e. that “everything is close by”.

- The societal health safety dimension encompasses specific issues about HIV / AIDS illness prevention, prophylactics, control and monitoring, and the systematizing and continuity of these processes.

- The civic pride dimension is related to ethnic dilemmas, orientated toward an HIV-positive person’s openness / closeness to society due to the diagnosis and taking of/retreating from responsibility without enabling one to protect one’s own health and the health of one’s environment.

- The communication dimension is related to informing society about HIV / AIDS as the initial duty and responsibility of medical workers emphasizing not only...
general knowledge, but specific information in various environments, including educational, health care and specific work environments.

- The labelling and stereotype dimension that emphasizes the existing stereotypes in society, which have been created by not being informed and a low degree of tolerance.

- The educational dimension means society’s need for knowledge, education, development and upgrading of competences in health safety issues in various education and upbringing institutions, training in various professions at universities and other higher institutions of learning, as well as in basic and post-graduate studies.

Obstacles for PLHIV in the labour market. Employers are members of society who are influenced by stereotypes existing in society concerning PLHIV and obstacles which reflect the following stereotypes: priority is given not to the competence of PLHIV but to the diagnosis of HIV; an employer’s fear and anxiety caused by his or her lack of awareness of the specific aspects of HIV result in irrational and negative decisions concerning an HIV-positive employee.

Need for employers to expand their knowledge on HIV-related issues. The awareness and accurate knowledge of employers on HIV / AIDS issues is positive active prevention concerning social exclusion of PLHIV. This enables the employer to concentrate on the individual’s professional qualifications, competences and competence that one has, which comes from his or her work experience, and not on the individual’s HIV diagnosis.

Possibilities of maintaining confidentiality in the labour market. PLHIV are not inclined to openly discuss their health situation with colleagues or employers because they are afraid of social exclusion and losing their job. Individuals who possess a high social status and financial possibilities allocate plentiful financial resources for treatment outside Lithuania, thus maintaining their confidentiality. “Other” HIV-positive people live under psychological tension caused by the diagnosis moral reproaches to themselves and physiological ailments, concealing their diagnosis from their environment.

Possibilities for the professional development of PLHIV in the labour market. PLHIV should not be restricted in selecting their profession; however precise criteria regarding the possibilities of PLHIV to work in specific professional fields should be defined, which would serve as a basis for the prevention of social exclusion of PLHIV based on objective criteria.

Need for PLHIV to empower themselves to protect their health in the work environment. An HIV-positive person must be competent on HIV prevention issues in order to be able to deal to the maximum extent with the existing situation by himself or herself, protecting their environment from potential unintended infection with/transmission of HIV and to know the ways to protect themselves and manage extreme situations that can be determined by the possibility to infect/get infected with HIV.

Need for PLHIV to inform their employer about their HIV diagnosis. An HIV-positive person must assume moral responsibility for informing their environment about his or her HIV diagnosis because the awareness of the employer and their environment represents strength and safety, whereas non-awareness means insecurity and psychological self-destruction by constantly living under tension due to a fear that the environment should not know about the diagnosis, always controlling themselves while communicating and behaviour and distancing themselves from customary relationships with one’s environment, restricting oneself from various interactions with others.

Need for NGO initiatives aimed at preparing PLHIV for the labour market and dissemination of information in work environments. HIV-positive people must overcome the psychological barrier inside themselves and empower themselves to
assume responsibility for themselves and the environment concerning prevention at their workplace. Therefore not only are NGO initiatives aimed at disseminating information in various work environments about HIV / AIDS specifics and prevention relevant, but also the sharing of experiences of PLHIV, seeking to eliminate entrenched stereotypes about HIV-positive people and see them not as a diagnosis or risk group but as persons, and professional and competent employees, who are integrated and who can be in harmony, irrespective of their diagnosed HIV.

**Need for societal initiatives and NGO initiatives regarding the development of social advertisements on HIV issues.** Social advertisements are an effective means of prevention regarding HIV-positive persons’ social exclusion and/or social discrimination.

**Need for NGO activity in educating society about the experiences of PLHIV.** The systematic and continual presentation of the experiences of PLHIV enhances the degree of societal tolerance and sensitivity, and create conditions to consciously understand the importance of human dignity in society. This awareness-raising strategy creates conditions for the integration of PLHIV into society and the labour market.

**NGO initiatives aimed at cooperating with various organisations and institutions and meeting with PLHIV.** It is important that NGOs perform the role of initiators of activities and change. For this reason, the meetings of NGO representatives with employers to present HIV-related problems and experiences of PLHIV in various contexts are relevant.

**NGO initiatives to meet with HIV-positive persons.** Positive strategies for the prevention of social exclusion of PLHIV include discussions of NGO representatives and conversations with PLHIV, empowering them to protect their own health and the health of their environment, assume responsibility for their lifestyle, and become aware of personal psychological barriers.
CHAPTER 5: RECOMMENDATIONS
Reducing the stigma of HIV and increasing tolerance of people with HIV/AIDS:

1. Persons living with HIV can help increase society’s tolerance of vulnerable groups by sharing their experience, disseminating the latest information, actively participating in conferences devoted to solving HIV problems, and working with organisations active in the HIV/AIDS area, especially NGOs. The experience of persons living with HIV is the most valuable information for other persons living with HIV. It often can be a stimulus to change their life strategy towards a positive and full life, to devote more attention to protecting their health, and accepting responsibility for the quality of their lives by taking concrete steps (acquiring a higher education or a professional qualification, etc.).

2. Social advertising is an effective means of preventing discrimination against persons living with HIV in order to avoid the social isolation of this group. (This measure can be financed with European social fund money.) It is especially important that non-governmental organisations be involved in the creation of social advertising and the organisation of social campaigns.

3. A need exists in the context of HIV/AIDS not to use the concept ‘risk group’, which is discriminatory, and instead to use the concept ‘sensitive group’, which is flexible and does not create any assumptions based on a mechanistic view.

4. Another effective and suitable way of informing society members on the topic of HIV/AIDS is tolerance celebrations. In this indirect manner society’s members better absorb and accept the received information, and a positive and comfortable environment promotes their tolerance of vulnerable groups and nurtures a feeling of community.

5. In informing society members about the experience of persons living with HIV, the involvement of NGOs is essential. The systemic and continuous presentation of the experience of persons living with HIV increases society’s tolerance and degree of sensitivity and creates the preconditions for perceiving the importance of human dignity. This information strategy creates natural preconditions for the more successful integration of persons living with HIV into both society and the work force.

6. In talking on the topic of HIV/AIDS with young people and adolescents and acquainting them with other sexually transmitted infections and thus increasing the tolerance of young people towards vulnerable groups, it is important to use authorities that are respected in society, especially by young people and adolescents, and that young people are especially inclined to listen to and imitate.

7. Research has revealed that it is imperative to improve the competency of journalists and other media representatives on the topic of HIV/AIDS. In presenting and supplying information about vulnerable social groups, media representatives should properly represent the concepts, not distort the supplied facts, not supply ambiguous or biased information and thus should not contribute to the intolerance of socially vulnerable groups.
The education sector:

1. In the opinion of all of the participants in the individual in-depth interview research, societal intolerance is caused by the society’s lack of information on HIV/AIDS. It is imperative to enlighten society’s members by acquainting them not only with the problems of HIV/AIDS and other sexually transmitted infections as well as the transmission routes but also by nurturing tolerance and reducing the stigma and discrimination of those with HIV. It is imperative to nurture society’s responsibility by organising public information campaigns.

2. During the research it was revealed that school teachers and school prevention work groups lack the skills to create and implement prevention programmes and to manage crisis situations in schools. The Ministry of Education and Science and/or the Teacher Professional Development Centre should continue the programmes for preparing education consultants and improving the qualifications of teachers and education assistance specialists, during which teacher competency would be increased on the topic of all of the sexually transmitted infections and the skills for managing crisis situations in schools be taught.

3. The Ministry of Health or institutions under its jurisdiction should initiate and organise qualification improvement courses for public health office specialists and other employees. They should be given an opportunity to regularly improve their qualifications in respect to HIV/AIDS and other sexually transmitted infections and to obtain not only medical but also psychological knowledge.

4. In nurturing understanding of HIV/AIDS and other sexually transmitted infections, the peer to peer principle, which is the best way of supplying information to adolescents, should be used. Information about sexually transmitted infections should include the entire school community: pupils, teachers, and parents.

5. In school, the topic of HIV/AIDS should investigated in the context of sexually transmitted infections rather than separately.

6. At an education institution, a public health care specialist (PHCS) should perform not just the role of consultant, but also conduct broader educational activities by working with the school’s teacher community, which is the main shaper of the attitudes at school.

7. An analysis of the experience of persons living with HIV revealed a need in schools to nurture the social competence of the pupils, encourage their consciousness about life’s general values, involve the parents, who will be supplied with information about HIV/AIDS that is based on scientific arguments, in the information process, and develop and expand the teachers’ specific knowledge connected with the context of HIV/AIDS. But the education must be professional and conducted by competent specialists (a team of teachers, public health care specialists, psychologists, and social workers). It is also important that persons living with HIV be involved in the education at the education institutions through the sharing of their experience with the school communities.

8. Focus discussions about HIV/AIDS with pupils are meaningfully begun in primary classes, but the information must be presented in an understandable form without oversimplifying it but while making it interesting to the pupils and encouraging them to perceive the importance of personal responsibility in society when they are capable of integrally perceiving and understanding the discussed ideas. The general conception of school oriented exclusively only to the achievements of the pupils does not allow a balance to be maintained among ethics, value, social, and civic education. This would create a precondition for shaping pupil tolerance not only for those living with HIV but also for all people regardless of their health status, sexual orientation, ethnicity, or sex.

9. Public health care specialists (working in the schools), who dispense accurate and profound specific knowledge, freely use the terminology, deeply understand human anatomy and physiological processes and are able to accurately and thoroughly
answer any relevant questions raised by the pupils, should be more involved by the schools in supplying information on health questions. Objective education on health questions is directly connected to the lecturer’s subject and competency, but this competency must be integral with competency in social, educational, and classroom management and self-control.

**The health care sector:**

1. A need exists in Lithuania for secondary HIV prevention, i.e. treatment must be employed as soon as possible, and people with HIV must be educated about the mandatory systemic use of medicine and the negative consequences on the body of desultory medicine use. Therefore a need has arisen for the professional and psychoanalytical assistance for persons living with HIV. The respectful behaviour of the health care specialists working with them is important for persons living with HIV. The occurrence of inadequate behaviour and emotional reactions by physicians and/or nurses diminishes not only the human dignity of the person living with HIV, but also the professional dignity of the professional medical community.

2. By separate order of the Minister of Health of the Republic of Lithuania it is necessary to prepare the description of a health care procedure for persons living with HIV, i.e. a procedure for patient care, which would establish who is responsible for the long-term, lifelong care (for ordering testing on time in accordance with a 2004 Ministry of Health order, ensuring the patient visits an infectologist or other specialist for specific antiviral treatment, etc.). The approval of such a document would give health care specialists more clarity concerning their responsibility in providing services to persons living with HIV, especially in Lithuania’s rural regions, as well as give those living with HIV more clarity concerning the obtaining of timely health care services.

3. The study revealed a need for the development of the emotional intelligence of medical personnel, a change in value attitudes, respectful behaviour with persons living with HIV, goodwill, sensitivity, and empathy. A need for the development of the multiple competencies of medical personnel and other public health care specialists in the areas of communication, situation management, conflict prevention and management, self-control, active listening, and consultation in integrating the social – psychological nuances was revealed in this context.

4. The study revealed a need for raising the competency of psychologists on HIV/AIDS questions, developing their social competency, and increasing their emotional intelligence. It also revealed a need for an anonymous assistance/information telephone line devoted to just persons living with HIV.

5. The founding of consultation services, telephone lines, or consultation offices is necessary in the small cities, towns, and rural localities, where persons living with HIV have no opportunity to consult specialists, obtain accurate information, or visit medical personnel as needed.

**The social services and labour sector:**

1. It is imperative to teach employers about HIV since they create the preconditions for developing tolerance and understanding as a prevention of social isolation in the context of the labour market.

2. It is imperative to expand the knowledge of employers on HIV questions. Suitably informed employers with accurate knowledge on HIV/AIDS questions create the preconditions for (re)integrating persons living with HIV into the labour market, thus reducing their social isolation. Possession of accurate knowledge about HIV/AIDS allows an employer to focus not on a person’s HIV diagnosis but on the professional qualification, acquired knowledge, and competency he or she possesses. It is also important for employers to have tax exemptions for hiring persons living with HIV.
3. It has been proposed that the Law on Social Enterprises of the Republic of Lithuania be amended by including social groups of risky persons into groups of purposeful persons, who acquire the right to state assistance after they find employment.

4. It is imperative to define accurate criteria for the possibility of persons living with HIV to work in specific professional areas, which, due to objective criteria, would prevent the social isolation of persons living with HIV.

**The role of NGOs:**

1. Important NGO initiatives in encouraging the founding in large and small cities of AIDS centres, which are the first opportunity for a person living with HIV to obtain the necessary information, assistance, and testing. Such centres could become centres for persons living with HIV to assemble, where HIV positive people could share their experience and trials as well as discuss problems and possible strategies for their solution.

2. The study revealed a need for the creation of new NGOs or the unification of existing NGOs into coalitions (unions) in order for them to have greater political power.

3. Incarceration facilities need informal consultants, who are themselves persons living with HIV and can share their experience with convicts living with HIV. The dissemination of their experience of life with HIV and the supply of accurate information about HIV/AIDS to convicts is an excellent alternative to consultations by a psychologist, which often lack a specialist’s understanding of the specific nature of HIV/AIDS.

**Merits of the study**

- This is the first known study of this nature in Lithuania and was conducted using a qualitative research strategy in order to determine the obstacles existing for the full social integration of persons living with HIV/AIDS;

- Specialists with a great deal of experience in the area of qualitative research conducted the study and analysed the study results. This allowed very important insights into the analysed problem to be formulated.

- It will be possible to compare the study results with the shared experience and analogous studies from other countries.

- The conducted study has focused the attention of the responsible institutions on the HIV/AIDS problem, which will perhaps help solve the problems of people with HIV/AIDS and create opportunities to obtain better health care services and opportunities to study and work.

**Deficiencies of the study**

- In the study, 20 individual in-depth interviews were conducted and 3 focus group discussions were held. Although the size of the study is sufficient according to qualitative research methodology, more respondents could have been questioned in the study. But this was not done due to time and resource constraints.

- The group of respondents in the individual in-depth interviews consisted of people questioned from two non-governmental organisations working in the area of HIV/AIDS. Greater NGO participation would have been an advantage but the participation of 2 NGOs was determined by the limited resources and short project time.

- In organising the focus group discussions, it was impossible to assemble all of the individuals competent in the area of HIV/AIDS despite all of them having been invited several times.
Lessons learned in Lithuania during the study

- In conducting a study and interviews, it is important to maintain a correct balance, not deviating from the study’s main goal and, at the same time, not hindering the study’s respondents from sharing their individual experience, not interrupting them, and not rushing them. Whether the questions were clear to the study participants was taken into consideration and they were ready to answer all of the respondents’ questions.

- In conducting individual in-depth interviews, it is important to select a suitable location for conducting the interview. Whether it was convenient for the study respondents to reach it on foot or by vehicle was taken into consideration. The importance of the warm-up questions is extraordinarily relevant. No outside noise should distract the person. It is necessary create a cozy atmosphere, not to rush, get to know them in the beginning, act helpfully and respectfully, and when necessary to take a break.

- It is necessary to more actively collaborate with non-governmental organisations and their members in order to effectively reach persons living with HIV/AIDS, but also to strive to question those people with HIV/AIDS who have the most experience.

- It is necessary in a study to think about how the individual in-depth interview and focus group respondents can be motivated to participate in the study and share their experience. This motivation can vary depending on the respondents, their place of residence, education, and other subjective reasons.
CHAPTER 6: APPENDICES
Appendix 1. Guide for individual interviews with PLWHA

Attitude toward HIV-positive persons

BLOCK I (max 5 min). I am an interviewer from the National Institute for Health Development. Your decision to participate in the interview will mean the following: you will participate in an interview, you will use a pseudonym during the interview, the interview will be audio taped and transcribed verbatim, and after transcription, the anonymous audiotapes will be destroyed. You also have to read the consent form. Do you agree to participate in this interview?

- Age
- Gender
- Ethnicity
- How long have you known that you have HIV?
- Do you have children?
- Yes: Do they have HIV?

BLOCK II (max 15 min).

What does it mean to be HIV positive? Some words, things that come to mind…

What does it mean to you to be living with HIV/AIDS? What else could it mean, for example to other people?

How do you think people who are PLWHA, are perceived? What are the attitudes towards PLWHA? In your mind, what are the differences between HIV positive persons and HIV negative persons?

Some previous studies show that when people find out that they have HIV, some things in their lives can really change. What kind of changes can they be?

Could you tell us about the ways in which HIV has changed your life? What do you do differently in your life now? What has been the biggest change?

How has your behaviour changed now towards other people? Do you feel you relate to yourself differently? How?

Who knows you have HIV? Family? Friends?

A: about those who know: How did they come to know? (ask specifically for each category mentioned) How long have they known? Are you close? Do you discuss HIV?

B: about those who do not know: what has impacted your decision not to tell them? How has it come about that you have not told them?

Is it difficult to live with HIV?

A: No, it is not difficult: But do you think that it is difficult for other people to live with HIV? Have you ever had trouble related to HIV? When was that? Who was involved? How did other people feel about that? What did you do about it? Was that the only person/time you have had trouble? (Please do not mention names or other details)

B: Yes, it is difficult: When is it most difficult? When was the last time you had trouble related to your HIV status? Who was involved? How did other people feel about that? What did you do about it? Was that the only person/time you have had trouble? (Please do not mention names or other details)

Thank you for those very valuable responses so far. Is there anything we missed?
BLOCK III (max 40 min)

We will move on to public sector topics now and discuss education, employment and health care.

Speaking about education: how do you think PLWHA do in our education system? How are they doing in kindergartens? Secondary schools and higher schools of education? In vocational training? In universities?

What sorts of problems, in your opinion, might PLWHA encounter in the Lithuanian education system? In kindergartens? Secondary and high schools? In vocational training? In universities?

Where have you studied/are studying now? A private or state institution?

Do you feel the need/want to study more or learn a new skill? Is it related to HIV?

Does anyone in your educational institution know that you have HIV? Who knows/has known? How does the knowledge that you have HIV impact your opportunities to study/train? When was the last time you had trouble at school because you had HIV? When was that? Who was involved? What were the attitudes of others? What did you do about it?

Was that the only person you have had problems with in educational institutions? (Please do not mention any names or details).

Have you ever been treated differently in an educational institution because you have HIV? How was this manifested? Do you know of other people having been discriminated against?

What should the teachers, education specialists and policy makers do to make access to education easier to PLWHA? How could education professionals support PLWHA?

In your opinion, are the education institutions ready to accommodate the needs of PLWHA?


Do people at the educational institution know that he/she has HIV? Who knows? How is HIV impacting his/her chances for further study? When did he/she last have problems because of the HIV positive status? (please do not mention any names). Has your PLWHA child ever been treated differently upon entering an educational institution? At kindergarten, or school? Do you know of any cases of discrimination from other people?

What would PLWHA children and their parents need from teachers and education professionals to make education more easily accessible to them?

How could teachers and education professionals help PLWHA children and their parents?

In your opinion, are the Lithuanian educational institutions ready to accommodate the needs of PLWHA children?

Let’s move to the topic of employment.

What could be said about employment and work opportunities for PLWHA in Lithuania?

Do you have paid employment at present? In what sector?
What problems can PLWHA face when working or seeking work? How has HIV impacted your opportunities at work? How has it affected your career?

How has HIV impacted your ability to work? Does it influence your decision to seek certain types of jobs? Would you have a different job if you were healthy?

Do people at work know you have HIV? Who knows? When did you last have problems at work because you have HIV? Which colleague/partner was it with? How did other people perceive it? What did you do? Was that the only person you have had problems with? (Please do not mention details)

Have you ever been treated differently because of HIV? How is this manifested? Do you know of any cases of discrimination from other people’s experience?

What would PLWHA need from employers to accommodate their needs and make work more easily accessible? How could employers support the PLWHA?

In your opinion, are Lithuanian employers ready to accommodate the needs of PLWHA?

Now let’s talk about health care.

Studies show that HIV transmission is related to several risk behaviours. Have you ever injected drugs? Do you consider yourself dependent on drugs?

Have you ever earned money by selling sex?

Do you have sex with men only, men as well as women, or women only?

How is your health? Is HIV causing health problems for you?


Which other doctors should you see? If there is a perceived need, why have you not sought help? Is this related to HIV?

Which doctors know that you have HIV? How do you go about deciding whether you should tell them or not?

Are you on ARV treatment?

Is access to medical services a problem for you? May the reduced access to medical services be related to HIV?

Have you ever been treated differently by medical staff because you have HIV? How is this manifested? When did you last have problems with medical services because you have HIV? When was this? Which medical personnel were involved? How did the others react? What did you do? Was that the only person you have had problems with in the health care system? Do you know of examples of discrimination from other people’s experiences? (Please do not mention any names or details.)

What would PLWHA need from doctors and other medical personnel, to make medical services easily accessible to them? How could medical personnel help the PLWHA more?

In your opinion, are the medical professionals ready to accommodate the needs of PLWHA?

How is the health of your child? Does he/she receive medical help? Which doctors does s/he see? An infectologist? A GP? A psychologist? A paediatric doctor? Who else? Which other doctors should s/he visit? If there is a perceived need, why does s/he not go to doctors? Is this related to HIV?
Which doctors know that your child has HIV? How do you go about deciding whether to tell doctors that your child has HIV?

Does s/he receive ARV treatment? Is accessing medical care problematic for your child? May it be related to HIV?

Has your child ever been treated differently because s/he has HIV? How is it manifested? When was that? Which doctor/medical personnel were involved? How did others react? What did you do? Was that the only person your child has had problems with? (Please do not mention any names or details here)

What would children living with HIV need from doctors and medical personnel to make access to health care easy for them? How could medical professionals help children with HIV more?

In your opinion, are Lithuanian medical establishments ready to accommodate children living with HIV/AIDS?

Have you ever been treated badly by the personnel of NGOs who provide services for PLWHA? How is this manifested? When was the last time you had problems at an NGO? Who was involved? How did the other people react? What did you do? Was that the only person you had problems with in an NGO? Do you know any cases of discrimination from other people? (Please do not mention any names or details here.)

What would PLWHA need from NGOs and volunteers to make services more accessible to PLWHA? How could the personnel of NGOs help PLWHA more?

In your opinion, are the NGOs of Lithuania capable of accommodating the needs of PLWHA?

Is there anything important that we did not discuss? Are there more areas where the PLWHA face challenges in society?

What do you think should be done to make PLWHA and their problems more understandable to our society?

What could/should the state do to make the life of the PLWHA better?

Who should offer these services? NGOs, the government, the private sector, the church?

Which services should definitely be available free of charge for PLHWA?

What could the PLWHA in Lithuania do themselves to make their lives better?

Would you like to add anything? Anything that remained unclear or unsaid?

Thank you very much. Your responses are very valuable to us.
Appendix 2. Guide for focus group with representatives institutions

Guide for focus group with educators

1. Explain the rules, introduction.
First introduce yourself one by one, tell how old you are, in which type of educational facility you work and what your position is.

2. Attitude to HIV+, perception of HIV+
What is your first association when you hear that a person is HIV-positive?
How serious and topical is the problem of HIV/AIDS in Lithuania today for the students at different stages in their education at various educational institutions?
Do people with an HIV-positive status pose any threat to others living without HIV? Why?
Should HIV-positive people be isolated from others during the educational process? Why do you think so?
Do you think there are any limitations to HIV-positive people in selection of profession?
What do you think, which limitations should be imposed on HIV-positive people during the selection of a profession?

3. Situation of HIV+ in the educational system
Have you faced the problem of HIV personally? Would you explain this in more detail?
Has this problem emerged in your educational institution? Tell about these cases in more detail.
How, in your opinion, do HIV-positive people feel in our educational system?
Which problems, in your opinion, may emerge among HIV-positive people in our educational system?
Does our system take into account the demands of HIV-positive people? To what extent? How is this displayed?
Are there people in your educational institution who care about HIV-positive problems? Yes/No. What is the status of these people and their activity? Are these people involved in developing training courses, activists involved in the problem, or those who are themselves infected with HIV?
Does your educational facility or staff undertake any efforts to support HIV-positive people? Tell more.

Separate questions for representatives of pre-schools
Are there limitations for HIV-positive children in getting into kindergartens? Why? If yes, where should they go? Give examples from your practice.
Are there constraints for children who do not have HIV, but having HIV-positive parents? Why?
Is it possible to say that HIV-positive parents have equal chances in putting their child in a kindergarten as much as normal parents do? Tell more.
Parents can hide their status or the status of their child. Does anyone check the HIV status of children brought to the kindergarten? In what way?
What would be the best solution – to isolate HIV-positive kids in the kindergarten or integrate them with others? Why do you think so?

**Special questions only for representatives of schools of general education and vocational schools**

Are there constraints for HIV-positive kids when they enter/go to school? Why? If yes, then where should they go? Give examples from your practice. If not, should there be constraints adapted and why do you think so?

What kind of difficulties arise for those studying in a vocational school? Explain in greater detail, providing examples.

What kind of limitations are there for the parents of HIV-positive children, are there special requirements that applied? Provide examples from your own experience. If not, should they be applied and why do you think so?

Are there perhaps separate classes for those that are HIV-positive in school? If so, do you think that it is ethical? If not, is that the way it should be?

In your opinion, what would the best solution be for HIV-positive students – to isolate them or have them study together with the other students? Why do you think so? Explain in greater detail.

**Special questions for representatives of higher education institutions**

What kind of problems arise for students in Lithuania who are HIV-positive that are linked with studies at institutions of higher education? Why do these problems arise? If there are not any, what kind of problems could arise?

Is it compulsory to provide a medical certificate about the lack of HIV infection upon entering a university? Perhaps there is a requirement that is applied for those who are already studying? Do you think that this kind of certificate is necessary? Yes/No/. Why do you think so?

What would be the best solution for HIV-positive students – to isolate them or create possibilities for them to study together with other students?

**Questions to all**

Summing up, is it possible to say that there are no formal barriers for PLWHA receiving or continuing education?

Should HIV-positive students or their parents speak openly about their HIV-positive status? Why do you think so? Do you know cases where HIV-positive students openly stated their diagnosis to others? What happened? Has the attitude changed toward such people? In which way? Did it create additional problems for those who were HIV-positive?

Have you heard about cases of discrimination against those who are HIV-positive by an educational institution, teachers, students, pupils, or other employees of the educational institution? Explain specific cases in greater detail.

Should the study curriculum in universities include special courses on HIV/AIDS? Why is it important/not important? Should it be a separate subject, or separate themes integrated in a few courses? Give an argument for your statements. What should the competence be of the teacher? What kinds of methods would be most effective? What kind of topics should be discussed in class?

At what age does it make sense to talk about the problem of HIV/AIDS? Why do you think so? Explain in greater detail. Perhaps you can provide examples from your own experience.

**Conclusion (15 min.)**

In your opinion, what should be done to make the problems of PLWHA more understandable to society? Who possesses the primary and basic responsibility? Why do you think so?
What could our state do to make the lives of PLWHA better and fuller? What could PLWHA do to improve their lives in Lithuania? What should be done?

**Thank you for your participation in the project.**

**Guide for focus group with employers**

1. Explain the rules, introduction.

First introduce yourself one by one, say how old you are, in which type of health care facility you work and what your position is.

2. Attitude towards HIV-positive persons

What is your first association when you hear that a person is infected with HIV?

Why is the problem of HIV/AIDS important and relevant to Lithuania today? How does this importance or relevance manifest itself? Or perhaps it isn’t relevant? Why do you believe so?

Should HIV-positive people be isolated from others during the working process? Why do you think so?

What kind of difficulties arise for PLWHA in selecting a profession? Provide examples.

Does Lithuanian legislation limit the choice of profession for those who are HIV-positive in any way? Provide examples.

Which constraints, in your opinion, should be applied on those who are HIV-positive when they choose a profession?

Where are the majority of PLWHA working now? In which professional sphere?

3. Situation of PLWHA in the labor market

How would you describe the situation for PLWHA at the labor market?

Do you think that the system of employment existing now in Lithuania take into account the needs of PLWHA? Perhaps you could provide examples proving your replies.

In your opinion, are employers in Lithuania ready to meet the demands of HIV-positive persons?

Which problems do PLWHA face in searching for a job?

Have you encountered the problem of HIV yourself? If so, talk about it in greater detail.

Has such a problem emerged in the organization, you represent? If so, explain it in greater detail.

Is there any problem in employing to those who are HIV-positive? What are the obstacles that arise?

How is this problem dealt with in your organization?

In your opinion, how topical will the problem of employment for those who are HIV-positive be in the future? What could be the methods in solving this problem?

4. Opportunities for professional growth for PLWHA

Are there HIV-positive people in your company? If so, tell more. What is their position, what functions do they carry out?

How would an HIV-positive person get employed in your company? Is it possible? If so, what position could they take up? What could he/she do specifically in your organization?
How compatible are such terms as “HIV-positive” and “career growth”?

Should staff be tested for HIV? Why? Do you check your personnel for HIV? Yes/No. Is it useful and necessary? For the person, the organisation, or society?

Questions to management heads

If you learned that one of your employees was HIV-positive, how would you react? What would you do? Why would you behave like this? Is it important to look at the views of other members of the team?

It is a well-known fact that many HIV-positive people prefer to hide their status. Even if they need a certificate to demonstrate at work, it is easy to make a fake certificate, since people from health care facilities issue such certificates for HIV-positive persons. What do you think about such a practice? Why does it exist?

Questions for middle-level managers

Are there people who are HIV-positive in your company? How do you treat them? What is your attitude towards these people?

If you learned that one of your colleagues was HIV-positive, how would you react? How would you behave?

Should the staff know that they work together with PLWHA? Why?

Questions to HR service

Should people be asked to pass an HIV test before being employed? Why?

Questions to all

Summing up, should PLWHA speak about their status? Why do you think so? Do you know of cases when PLWHA openly told others about their status? What happened next? Has the attitude changed at work? In which way? Has it created extra problems for PLWHA?

What can employers do to make the job opportunities more accessible to HIV-positive persons? How should they support HIV-positive persons?

Conclusion (15 min.)

In your opinion, what should be done to make the problems of PLWHA more understandable for society?

What could our state do to make the lives of PLWHA better and fuller? What could PLWHA do to improve their lives in Lithuania? What should be done?

Thank you for taking part in the study.

Guide for focus group with health care professionals

1. Explaining the rules, introduction.

First introduce yourself one by one, say how old you are, which type of medical facility you work in and what your position is.

2. Attitude towards HIV-positive persons

What is your first association that you think of when you hear the words “HIV-positive person”?

What problems can HIV patients encounter if they need medical assistance? For example, if an HIV-positive person has pneumonia or is ready to give birth to a child?
How can such patients find out about the status of their health? In what institutions can they be provided with information? What specialists inform them about their health status? What steps are taken by doctors and patients when they find out about the diagnosis? Is there perhaps a consultation? Is there a phone hotline or something similar? What specialists provide information to HIV-positive persons on a continual basis? What is this information about?

Are HIV-positive persons provided with the necessary medicine?

Are drugs that maintain one's immune status available and affordable? If not, what kind of assistance is provided to these people? Where they can turn to for financial assistance? Is the system of assistance effective?

Are there any HIV-positive groups for which it is a priority to get ARV-therapy? What are those groups? Why should they get this therapy first? Argue your case using examples.

3. Attitude of doctors towards HIV-positive persons

What is the attitude that prevails among those working in your institution and in general among those in your profession?

In your opinion, are HIV-positive persons fully-fledged members of society and good workers?

Should patients with and without HIV be put in the same ward in a hospital, or should HIV-positive persons be isolated? Should they be treated by the same doctor? In which cases? Why do you believe so?

Can you say that doctors from your environment have a different attitude toward HIV-positive persons? If so, what reasons have influenced your opinion? Why? Try to remember cases from your own experience or the experience of your colleagues.

Would you assert that doctors and nurses are biased against HIV-positive people? Why do you believe so?

One HIV+ respondent told us a story of her mother, who works as hairdresser. When one of her permanent clients, a cardiologist, learned that her daughter has HIV, he stopped using her services. How would you evaluate such situation? How would you behave? Why?

4. Attitude towards confidentiality

Now let's talk about confidentiality. The majority of our HIV+ respondents argue that it is better to keep the diagnosis a secret. The primary reason is to not cause additional problems in communicating with others, getting a job, an education, etc. Should the diagnosis be kept in secret or should people around be aware that a person is HIV-positive? Why?

In the course of the study, we have found that many are afraid of disclosing their secret to doctors in municipal clinics, as they are afraid they will not hold to the principle of confidentiality and will spread the information. How much do the doctors and nurses comply with the ethical code when they encounter HIV-positive persons?

5. Involvement in working with PLWHA

Are there any activities in the medical institution you work in that support or help PLWHA? Perhaps there are specific programs that are implemented? Explain in greater detail. Who is responsible for it? If so, are these programmes adequate? Are they effective? Perhaps there are difficulties that arise in implementing them? How could these activities be expanded?
If they are not effective or there are none, why doesn't your medical facility have such programs? HIV has a long history in Lithuania. Are there any specific reasons why your medical facility does not pay enough attention to the issue? What would be the engine forcing medical facilities in Lithuania to pay more attention to developing programs for PLWHA?

UNAIDS and other international organizations recognise the importance of confidentiality, the opportunity to receive an education, work and all necessary information. What would this mean for Lithuania?

**Conclusion (15 min.)**

In your opinion, what should be done to make the problems of PLWHA more understandable to society?

What could our state do to make the lives of PLWHA better and fuller? Whose primary and basic responsibility is it? Why do you think so?

What could PLWHA do to improve their lives in Lithuania? What should be done?

**Thank you for taking part in the study.**

**Guide for focus group with NGO representatives**

1. **Introduce yourself, and explain the rules.**

First introduce yourself one by one, say how old you are, which type of NGO you work in and what your position is.

2. **Attitude towards HIV-positive persons**

What is your first association when you hear a person is infected with HIV?

How serious and topical is the problem of HIV/AIDS in Lithuania today? Among which groups is infection most prevalent?

Has this problem received the attention of NGOs? Why? Does your organization devote attention to this problem? Provide examples.

If you compare the situation with previous years, how has the scope and meaning of this problem changed – has it increased, decreased, or stayed the same? Why did it happen this way?

How is your work connected to the problems of HIV-positive persons? Explain in greater detail. Do you often encounter HIV-positive people in person? Explain how and where this most often occurs.

What kind of viewpoint is dominant among those in society towards HIV-positive persons in Lithuania? What could you say about the viewpoint of doctors and other medical workers? What about the viewpoint of employers? What about that of employees of educational institutions?

3. **Discussion about the accessibility of education, employment and health care**

Now let’s talk in more detail about the problems PLWHA may face in such spheres as education, a specific profession, and health care.

Which problems can those who are infected face if they want to receive an education or upgrade their skills in Lithuania? If there are any obstacles that arise in receiving an education, what are they? Perhaps you remember specific cases?

Which problems can HIV-positive persons face when they seek employment in Lithuania? Specify cases that you know of in Lithuania.
Are laws enforced in practice, which regulate the work of those who are HIV-positive (it says that HIV cannot be a reason for firing a person)? Try to remember the cases that you know of.

Perhaps you know cases when an employer is not against having PLWHA in his company? Would you name some of these organizations?

What problems can PLWHA face, if they want to get medical assistance?

Do these people receive the necessary medical assistance? Are drugs that maintain one’s immune status available and affordable? If not, what kind of assistance is provided to these people? Where they can turn to for financial assistance? Is the system of assistance effective?

Is attitude of doctors towards HIV-positive persons different? How is it reflected? What could be the reason for this? Tell more about specific cases that you remember.

Can we say that medical staff have negative views towards HIV-positive patients? How do these views manifest themselves?

After carrying out the study with HIV-positive persons, he became clear that they feared disclosing their status to doctors in municipal clinics, as then anyone could find out. How much do doctors and nurses stick to the ethical code, which protects HIV-positive persons?

Is there any difference in the attitude of NGO workers towards different groups of PLWHA? Why do you believe so? How does this manifest itself? Provide examples.

Which problems of PLWHA should be resolved first – physical problems (e.g. supply of necessary medicine), or social problems (relationships with employers and medical staff?) Why do you think so? What are the problems that arise in giving priority to one of these spheres? Why?

Should the diagnosis be kept secret, or should people who encounter PLWHA every day know that there is an HIV-positive person in their environment? If so, then why, and if not, they why?

UNAIDS and other international organization emphasize the importance of confidentiality, the possibility of freely receiving an education, job and adequate information. What would this mean for Lithuania?

**Conclusion (15 min.)**

In your opinion, what should be done to make the problems of PLWHA more understandable to society?

What could the state do to make the lives of PLWHA better and fuller? Whose primary and basic responsibility is it? Why do you think so?

What could PLWHA do to improve their lives in Lithuania? What should be done?

Thank you for taking part in the study.
Appendix 3. Tables

Community Mapping of Lithuania

Table 1. The prevalence of HIV infection and AIDS in Lithuania in 2008

<table>
<thead>
<tr>
<th>COUNTIES</th>
<th>Number of PLWHIV at the end of the year</th>
<th>Prevalence of HIV per 100 000 persons</th>
<th>Number of persons with AIDS at the end of the year</th>
<th>Prevalence of AIDS per 100 000 persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lietuva</td>
<td>1242</td>
<td>37,1</td>
<td>117</td>
<td>3,5</td>
</tr>
<tr>
<td>Alytus</td>
<td>34</td>
<td>19,4</td>
<td>1</td>
<td>0,6</td>
</tr>
<tr>
<td>Kaunas</td>
<td>75</td>
<td>11,2</td>
<td>14</td>
<td>2,1</td>
</tr>
<tr>
<td>Klaipėda</td>
<td>387</td>
<td>102,3</td>
<td>33</td>
<td>8,7</td>
</tr>
<tr>
<td>Marijampolė</td>
<td>17</td>
<td>9,5</td>
<td>2</td>
<td>1,1</td>
</tr>
<tr>
<td>Panevėžys</td>
<td>14</td>
<td>5</td>
<td>4</td>
<td>1,4</td>
</tr>
<tr>
<td>Šiauliai</td>
<td>64</td>
<td>18,5</td>
<td>6</td>
<td>1,7</td>
</tr>
<tr>
<td>Tauragė</td>
<td>6</td>
<td>4,8</td>
<td>1</td>
<td>0,8</td>
</tr>
<tr>
<td>Telšiai</td>
<td>51</td>
<td>29,6</td>
<td>4</td>
<td>1,7</td>
</tr>
<tr>
<td>Utena</td>
<td>17</td>
<td>10</td>
<td>2</td>
<td>1,2</td>
</tr>
<tr>
<td>Vilnius</td>
<td>202</td>
<td>23,8</td>
<td>32</td>
<td>3,8</td>
</tr>
</tbody>
</table>

The number of persons were in penitentiaries is not distributed by administrative territory

|          | 378 | --- | 18 | --- |

Geographical distribution of PLHIV in Lithuanian counties

Map 1: Distribution of HIV prevalence in 10 counties of Lithuania (2008)

Lithuania is divided into 10 counties, 44 districts and 60 municipalities. HIV cases have been identified in all 60 municipalities in the 10 counties of Lithuania.
Selection of regions for the study

According to the Department of Statistics of the Government of the Republic of Lithuania, the following are data for 2008 from the counties: Vilnius, Klaipėda, Šiauliai, Telšiai and Alytus have the highest number of PLHIV in Lithuania. Four of these counties were selected for the PLHIV sample in this study. All counties are in different geographical territories of Lithuania (East, West, South and North). Four of these counties were selected for a sample of PLHIV individual interviews. The cities of Vilnius, Klaipėda, Šiauliai and Alytus within these counties were selected.

The main criteria for the selection of counties and cities (Vilnius, Klaipėda, Šiauliai and Alytus) were as follows:

- The HIV prevalence rate and the existence of socially vulnerable risk groups;
- Specificity of the region in the context of the actual geographical location;

### Table 2. Cities selection criteria

<table>
<thead>
<tr>
<th>Cities</th>
<th>Information about city</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vilnius</td>
<td>Population in 2009 – 546 733</td>
</tr>
<tr>
<td></td>
<td>All diagnosed HIV cases in Vilnius city during the period of 1988 – 01 August 2009 – 255 cases</td>
</tr>
<tr>
<td></td>
<td>In this county is Vilnius - the capital and the largest city of Lithuania; a great number diagnosed cases of HIV/AIDS, a major supplier of tourism services, intense migration, and a big prevalence of risk populations.</td>
</tr>
<tr>
<td>Klaipeda</td>
<td>Population in 2009 – 183 433</td>
</tr>
<tr>
<td></td>
<td>All diagnosed HIV cases in Klaipeda during the period of 1988 – 01 August 2009 – 415 cases</td>
</tr>
<tr>
<td></td>
<td>The city of Klaipeda is located in Klaipeda county. It is the only seaport and one of the largest cities in Lithuania. Despite the fact that it does not possess the largest number of inhabitants, it recorded a significant number of cases population of HIV infection and a big prevalence of risk populations</td>
</tr>
<tr>
<td>Siauliai</td>
<td>Population in 2009 – 126 215</td>
</tr>
<tr>
<td></td>
<td>All diagnosed HIV cases in Siauliai during the period of 1988 – 01 August 2009 – 58 cases</td>
</tr>
<tr>
<td></td>
<td>Smaller city in Lithuania</td>
</tr>
<tr>
<td>Alytus</td>
<td>Population in 2009 – 67 505</td>
</tr>
<tr>
<td></td>
<td>All diagnosed HIV cases in Alytus during the period of 1988 – 01 August 2009 – 30 cases</td>
</tr>
<tr>
<td></td>
<td>Smaller city in Lithuania</td>
</tr>
</tbody>
</table>

In order to select a sample of PLHIV for the in-depth interviews, this study used purposive and "snowball" sampling method. Selected criteria for purposive sampling:

1. Age
2. Gender
3. Mode of HIV transmission
4. Geographical distribution
5. Different risk groups (injecting drug users, men, having sex with men, commercial sex workers and others)

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* According to Lithuanian AIDS Centre data, in Lithuania on 01 August 2009 the main route of infection for HIV is injecting drug use. According to 01 August 2009 data, HIV infection through injecting drug use is 72.77 per cent, while the HIV prevalence index for 2007 – 2008 was 8 per cent in this risk group according to data from a study conducted by the Lithuanian AIDS Centre. Considering the current data, the majority of the study participants in the individual in-depth interviews consisted of persons who use injecting drugs now or who have used them previously.
In order to select a sample of “Mirror organizations” working with PLWHA for the focus groups, this study used also purposive and “snowball” sampling method. Selected criteria for focus groups for purposive sampling:

1. Working experience and competition in HIV/AIDS

2. Organizations from various kinds of institutions (health care, work, education and social services and NGOs)

**Appendix 4. Bibliography**


42. Resolution no. 1145 of 16 July 2002 of the Government of the Republic of Lithuania 'On the Amendment of Resolution no. 544 of 7 May 1999 of the Government of the Republic of Lithuania "On the List of Jobs and Activity Areas, in which Persons are Allowed to Work only after an Advance Check-up and Subsequent Periodical Health Check-ups for Infectious Diseases and the
Procedure for Checking the Health of these Persons’ (Valstybės Žinios, 2002, no. 73-3127).

Order no. 404/96 of 24 July 2001 of the Minister of Health and the Minister of Social Security and Labour of the Republic of Lithuania ‘On the Approval of the List of Medical Contraindications, due to which Persons Cannot Be Adoptive Parents’ (Valstybės Žinios, 2001, no. 66-2427)

Order no. 386 of 17 July 2001 of the Minister of Health of the Republic of Lithuania ‘On the Approval of the List of Diseases, due to which an Infected Person Cannot Be Appointed a Child’s Guardian (Foster Parent)’ (Valstybės Žinios, 2001, no. 64-2373)


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