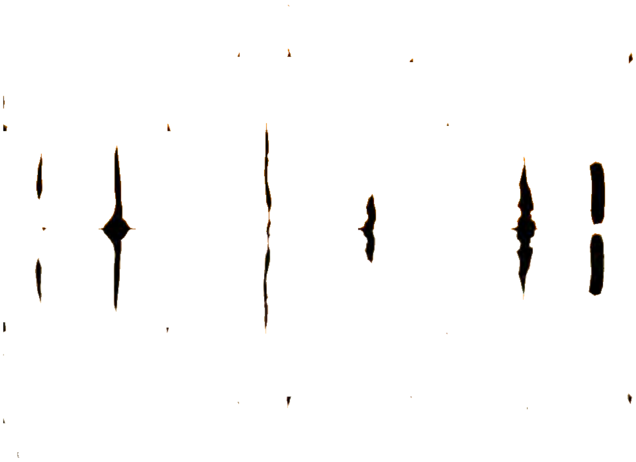
ESTONIA HIV
Leadership through
Accountability

THE PEOPLE LIVING WITH HIV STIGMA INDEX



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GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

Estonia

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The PLHIV Stigma Index is an initiative of four founding partners

Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral therapy
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CSO	Civil Society Organisation
FBO	Faith-based organisation
GFATM	The Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
ICW	International Community of Women Living with HIV/AIDS
LGBT	Lesbian, gay, bisexual and transgender
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
SRHR	Sexual Reproductive Health Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
WHO	World Health Organisation

Foreword

Many years ago I underwent a HIV test and the results showed that I was HIV-positive. I was confused and scared; I refused to believe that something like this could happen to me. I thought that I would become a cast-off. I thought that my relatives, friends and colleagues would turn away from me, that nobody would love me any more and everybody would be afraid of me. I believed that my life was at an end and I would die quite soon. At this point I had a tremendous number of questions; it was difficult to decide where to start.

I've been living with the HIV virus 18 years now. Yes, my life has changed, but life is ever-changing. Because of HIV I must make some adjustments to my plans but I do not need to give up my dreams of love, family, a career, children and friendship.

These fears that I had go to the heart of what this study is about – detailing the stigma and discrimination that Estonians living with HIV experience and feel. It is the first study on the topic, and was carried out by HIV-positive people.

We would like to believe that the action that arises from the findings of the study will help to improve Estonian HIV-positive people's quality of life, health and daily life so that people living with HIV will feel more able to ask questions, less fearful of the responses and the reactions of others, and be served better by all those who provide services.

Igor Sobelev
Chair Estonian Network of PLHIV

EHPV
Eesti HIV-positiivsete võrgustik
Estonian Network of PLWH

Acknowledgements

The Estonian Network of PLHIV would like to thank the Global Network of People Living with HIV (GNP+) and HIV in Europe for the financial and technical support that made this study possible.

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We also would like to thank Julian Hows, GNP + for technical guidance throughout the study; Laurel Sprague, GNP+NA, who reviewed the data analysis and provided technical support and guidance for the supplementary study concerning late testing and treatment included in this report; and Andrew Doupe, HIV and Legal Consultant, for additional technical assistance.

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Many thanks also to the study team: Aleksandr Petrenko, Denis Naumov, Svetlana Bridge, Oleg Konstantinov, Tatiana Mironova, and Aleksandra Barsukova, who conducted the interviewees; Rutt Vihtla and Kristel Toom, who processed the qualitative and quantative data; Asta Pajos, who coordinated the data input; and Livi Riivits-Arkonsuo, who undertook the data analysis.

Most importantly a special thanks to all HIV-positive respondents who voluntarily participated in the study and were willing to share their sometimes difficult experiences of living with HIV.

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Testing and Earlier Care

Contents

List of Tables and Charts

Tables

Charts

Executive Summary

This study by the Estonian Network of PLHIV is the first of its kind to be undertaken by HIV-positive people in Estonia, and aimed to collect information on stigma and discrimination against people living with HIV. The results show that HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services.

Methodology

This study used the People Living with HIV (PLHIV) Stigma Index developed by GNP+, ICW, IPPF and UNAIDS to undertake interviews, following a standard standard methodology. as laid out at www.stigmaindex.org[1]. The study was undertaken between November and December 2010, and involved a sample of 300 people living with HIV drawn from four cities and two prisons. In addition, qualitative and quantative questions were asked of a smaller sample of 87 respondents about barriers to accessing services and specific issues faced by people living with HIV[2].

Sample of respondents

The study found that HIV-related stigma was prevalent and an ongoing part of life for the people living with HIV in Estonia who took part in this study. Almost two-thirds of the respondents were men (63%, n=189) and almost two-fifths were women (37%, n=111). 80% of the respondents were between the ages of 25-39 with a further 13% between 20 and 24 years old. In terms of residency, 83% of respondents live in large cities, 14% in smaller cities and 3% in villages. The largest percentage of respondents, 42%, have been living with HIV for 5-9 years, while a further 28% for 1-4 years and 23% for 10-14 years. Further, 10% of respondents report having a physical disability other than HIV-related general ill health.

Nearly 40% of respondents lived with a spouse or partner; 17% had a spouse or partner but did not live with her/him; while 45% were single (unmarried, divorced or widowed). Nearly three-quarters of respondents reported that they were sexually active.

On average, 2.2 people lived together with the respondent at the time of the survey; with 8% (n=25) living alone. 136 respondents (45%) indicated that they had children with 37% living with their children aged 0-14 years of whom 56% were women. Two respondents,

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[1] Available at http//:www.stigmaindex.org

[2] The full report of the addittional study (across five countries) can be accessed at Late Testing, Late Treatment in English and Russian.

both women, indicated that one or more of their children were HIV-positive (3%); and two respondents reported that children who have been orphaned due to AIDS live in their household.

The largest group of respondents was people who use drugs (78%, n=232) with over half (51%, n=151) being former or current prisoners, and 43% (n=129) identifying both as people who use drugs and as prisoners or former prisoners.

The effects of poverty on the sample of people living with HIV are clearly evident. 24% of the respondents reported 'severe food shortage' (i.e. during a month there had been three or more days when respondents' household members did not have enough food to eat) with women reporting more food shortages than men. Furthermore, two thirds of respondents were unemployed with relatively more women than men among the unemployed as well as higher unemployment among respondents under the age of 30. Nearly two in five respondents reported no formal or only primary level education. In terms of income, 35% of respondents had a lower income, 33% middle income, and 31% higher income with relatively more women (43%) than men (25%) with a lower income.

Most respondents were Russian speakers (90%, n=271) with 29 Estonian speakers (10%). Estonian speakers were more likely than Russian speakers to be male (83% to 61%) and more recently diagnosed HIV-positive (59% compared to 32% were diagnosed in the last 4 years); while Russian speakers were more likely than Estonian speakers to be, or have been, people who use drugs and prisoners; and report much higher levels of food insecurity.

Major findings

Major findings concerning the experiences of people living with HIV by area are outlined below with the full findings, including the results of thequalitative interviews, presented in the **Conclusions**.

The study found that HIV-related stigma was prevalent and an ongoing part of life for the people living with HIV in Estonia who took part in this study.

Exclusion

- The majority of respondents (63%) reported that they had been gossiped about at least once in the last year with 39% indicating that it occurred, in whole or in part, because of their HIV-positive status
- Significant percentages of respondents reporting having been verbally insulted/harassed/threatened (39%), physically assaulted or threatened (24%), and/or physically assaulted (22%) at least once in the last year. Of these, 31% indicated being insulted/harassed/threatened, physically assaulted or threatened

(12%), and/or physically assaulted (10%) during the last 12 months, in whole or in part, because of their HIV-positive status.

- Over 60% of respondents feel that HIV-related stigma and/or discrimination is due to people not understanding how HIV is transmitted or are afraid of infection through casual contact.

Access to work and health and education services

- Significantly higher levels of discrimination were reported by respondents in access to residency/accommodation and work (approximately 25%) than in and health and education services (less than 10%).

Internalised stigma and fears

- Internalised stigma was prevalent: over 60% reported feeling guilt, 57% blamed themselves, 42% felt ashamed, and over 33% had low self esteem.
- 10% of respondents reported feeling suicidal with women reporting more suicidal thoughts than men (15% to 7%).
- The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (25%), not to marry (13%) and to isolate themselves from friends and relatives 812%).

Rights, laws and policies

- The Estonian Equal Treatment Act was known to 38% of respondents (n=113); of whom, 38% (n=43) had read or discussed it.
- During the previous 12 months, 34% of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- Twenty respondents reported that that they experienced a rights violation within the previous 12 months, of whom three had sought legal redress; of the 17 respondents who did not, the most common reason cited (50%) was belief that the outcome would be unsuccessful.

Effecting change

- In the previous 12 months, over 60% of respondents provided some form of support to HIV-positive people; while nearly 20% had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV.
- Over 80% of respondents felt unable to influence policies, laws and programmes at either national or local levels.
- In terms of the most important thing organisations should do to address stigma and discrimination, more than 40% cited advocating for the rights of all people living with HIV;

Estonia

Testing and diagnosis

- Seven percent of respondents (n=21) were referred for HIV testing when already symptomatic.
- Human rights violations associated with involuntary HIV testing[3] and being tested without consent[4] or any counselling[5] remain a challenge, as do the cost, time and distance in accessing HIV testing services.

Disclosure and confidentiality

- High levels of disclosure by respondents included to: health care workers (77%), other HIV-positive people (72%), spouses or partners (67%), and other adult family members (61%), injecting drug partners (57%), and social workers and other counsellors (51%);
- Disclosure within relationships remains an issue for some respondents, for example, 5% of respondents have not disclosed their HIV status to their spouse or partner, and 7% have not disclosed to injecting drug partners.
- Approximately half of respondents described disclosing their HIV status as an empowering experience.

Treatment

- 59% of respondents were taking ART with 94% indicating that they could access ART if needed.
- 40% of respondents had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children

- More than half of respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
- Ten respondents (reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis, all of whom identified as current or former people who use drugs.
- During the last 12 months, coercion by health care workers because of HIV-positive status was reported by 5 women (abortion), 4 women (method of giving birth) and 2 women (infant feeding practices).
- In relation to the prevention of vertical transmission (PVT) , 6% (n=5) of 84 women who had been pregnant indicated that they did not know that such treatment existed or they did not have access to ART (2%, n=2).

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[3] 7% of respondents were tested whilst undergoing other medical procedures (n=21).

[4] 21% of respondents were tested while in prison (n=64).

[5] Just over a third received no counselling at all; while nearly a third received only post-test counselling and 2% received only pre-test counselling.

Major Recommendations

The overall recommendation derives from the facts that among the sample there was low socio-economic status, including significant percentages of respondents reporting low levels of education and employment, as well as internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatising and discriminatory treatment), and 10% of respondents reported feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for the Estonian Network of PLHIV, civil society, the National AIDS Programme and the Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities for people living with HIV to become peer educators, capacity and network building, counselling, training, and income generation.

Supporting the existing work that is being undertaken, often with few resources, so that people living with HIV are placed at the centre of managing their health and wellbeing. Such an approach 'Positive Health, Dignity and Prevention'[6] ensures that people living with HIV are able to contribute as full partners in the response.

Other major recommendations directed to the Estonian Network of PLHIV, civil society, the National AIDS Programme and the Government are outlined below with the full recommendations presented in **Recommendations**.

Estonian Network of PLHIV

- Encourage and build the capacity of people living with HIV to advocate for their rights; be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes; and to provide support and assistance to people living with HIV individually, and through support groups and other local organisations.
- Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, including key populations, and in particular people who use drugs, current and former prisoners, and people with disabilities.

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[6] For more information on PHDP please go to: http://www.gnpplus.net/en/programmes/positive-health-dignity-and-prevention/positive-health-dignity-and-prevention/1728-new-resource-policy-framework-to-implement-positive-health-dignity-and-prevention

Civil Society

- Advocate for the rights of all people living with HIV, including key populations.
- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.

National AIDS Programme

- Given that there is a low level but consistent pattern of denial of the rights of people living with HIV in health care settings, including SRH rights:
    - revise pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV, including PVT;
    - review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV; and
    - scale up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, across all locations.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.
- Undertake and/or support research to strengthen the evidence base, including:
- Studies on the denial of sexual and reproductive health services to people living with HIV.
- Associations between low income level and severe food insecurity, and positive experience of disclosure.

Government

- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically addresses HIV-related stigma and discrimination, requires informed consent for HIV testing, protects confidentiality and provides redress for breaches.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing

HIV-related myths.

- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.
- Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Introduction

Background on HIV-related stigma and discrimination

Stigma is ‘an attribute that is deeply discrediting’ and results in the reduction of a person or group ‘from a whole and usual person to a tainted, discounted one’[7]. Thus, the ultimate effect of stigma is the reduction of the life chances of the stigmatised through discriminatory actions[8].

Discrimination involves treating someone in a different and unjust, unfair or prejudicial way, often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards those individuals who are stigmatised. In other words, discrimination is ‘enacted stigma’[9]. However, a person may feel stigma towards another but s/he may decide not to act in a way that is unfair or discriminatory. Discrimination can occur at different levels: individual, family, community or national[10].

HIV-related stigma often builds upon and reinforces other existing prejudices such as those related to gender, sexuality and race. For example, the stigma associated with HIV is often based upon the association of HIV and AIDS with already marginalised and stigmatised behaviours such as sex work, drug use and same-sex and transgender sexual practices[11]. HIV-related stigma affects those living with HIV and, often, those with whom they are associated, such as their partners or spouses, their children or other members of their households.

Internal stigma, also referred to as ‘felt’ stigma or ‘self-stigmatisation’ is a term used to describe the way a person living with HIV feels about him/herself, particularly if he/she feels a sense of shame about being HIV-positive. Internal stigma can lead to low self-esteem, a sense of worthlessness and/or depression. Internal stigma can also result in a person living with HIV withdrawing from social and intimate contact.

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[7] Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. New York: Simon & Schuster Inc.

[8] Ibid.

[9] IPPF (2008) HIV/AIDS Update Issue 13
UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes. UNAIDS best practice collection. Geneva.

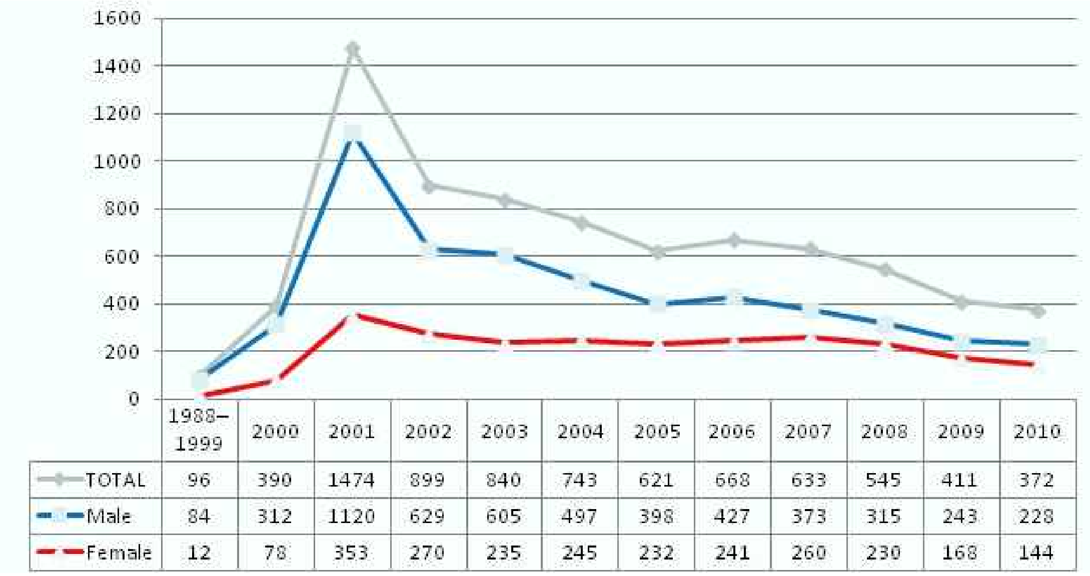
[10] UNAIDS (2005) HIV-related stigma, discrimination and human rights violations: case studies of successful programmes. UNAIDS best practice collection. Geneva

[11] Ibid.

Country Context

On 6th May 2011 it was announced that there were 7839 officially registered people living with HIV in Estonia, including 330 people who have been diagnosed with AIDS[12] More than two-thirds of these diagnoses were amongst men. The number of newly registered cases has been reducing since 2001, particularly among men.

Chart 1: Distribution of newly-registered HIV cases by sex: 1988-2010



	1988–1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
TOTAL	96	390	1474	899	840	743	621	668	633	545	411	372
Male	84	312	1120	629	605	497	398	427	373	315	243	228
Female	12	78	353	270	235	245	232	241	260	230	168	144

Source: National Institute for Health Development, 2011

The HIV epidemic in Estonia has largely spread through injecting drug use with secondary sexual spread from men who inject drugs to their female sexual partners. Two geographic regions, Tallinn and north east Estonia have been particularly affected. This pattern has not changed in several years. There is currently no evidence of the epidemic ‘generalizing’, that is affecting a large number of men who have not injected drugs, had sex with a woman who has injected drugs or had sex with another man.

About the Estonian Network of PLHIV

The Estonian Network of People Living with HIV (ENPLWH) was created in 2005 for people and by people living with HIV and AIDS.

Organizations mission statement:

To improve quality of a life of PLHIV, by involving of all interested stakeholders for providing psychological, social, advisory, legal aid, education and advocacy on availability of medical products and diagnostics for PLHIV in Estonia.

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[12] Rüütel, K., Trummal, A., Salekešin, M. and Pervilhac, C. (2011) HIV Epidemic in Estonia: Analysis of Strategic Information, The National Institute for Health Development.(Estonia)

Strategic directions of activity:

- Improvement of access to medical and non medical services and support.
- Lobbying and advocating on the rights of PLWH.
- Formation of the tolerant attitude of a society toward PLWH.
- Increasing of organizational ability of NGOs and support groups of the Network.
- Struggle against stigma and discrimination.

Objectives

The purpose of this study was to collect information on stigma and discrimination against people living with HIV in Estonia.

The specific objectives were to:

- analyse stigmatization and discrimination from the point of view of HIV-positive people;
- identify the extent to which HIV-positive people are informed of their rights and their access to redress in case of rights violations; and
- highlight the opinion of HIV-positive people on the quality of medical services they receive (e.g. diagnostics, ART and SRH).

Methodology

The study was conducted between November and December 2010, and involved a sample of 300 people living with HIV drawn from four cities: Tallinn (n= 102), Tartu (n = 24), Narva (n = 100) and Kohtla-Järve (n= 50), and from two prisons: Tartu (N = 16) and Harku (N = 8)). The prison sites were selected because of the high numbers of those incarcerated known to be living with HIV, and the ongoing work that PLHIV and other organisations are doing in these institutions.

Sampling: Potential participants were informed about the study by consultants, staff of infectious diseases hospitals, probation officers, staff of syringe exchange programmes and other organizations which provide AIDS-related services in Tallinn, Narva, Tartu and Kohtla-Järve. Participation was voluntary, though all participants received a gift voucher worth 100 EEK[13].

Inclusion criteria:

Participants were considered eligible to take part in this study if he or she

- was able to give consent to participate in the study;
- was older than 18 years;
- was able to speak in and write Estonian or Russian;

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[13] At the time the fieldwork was conducted Estonia was still using the Estonian Kroon (EEK) as its currency. 100 EEK at that time was approximately equivalent to €7.00, and would have enabled interviewee to buy modest foodstuffs, or enjoy a meal for two at a fast food /cafeteria type restaurant.

- was willing to answer the anonymous questionnaire;
- had not previously participated in the study;

Data collection instruments:

The study used the People Living with HIV (PLHIV) Stigma Index[14] (The Index) developed by and for people living with HIV. This is an initiative of four founding partners working together since 2005 - GNP+, ICW, IPPF and UNAIDS. The Index facilitates collection of information from people living with HIV to:

- enable people living with HIV to document their experiences;
- compare experiences across countries;
- measure changes over time; and
- provide sound evidence for policy and programme interventions.

The study tools, all in Estonian and Russian, which were completed during face-to-face interviews, included a structured questionnaires and informed consent form. The main questionnaire consists of 117 questions, most of which are multiple choice questions. A supplementary set of questions (regarding experiences of late testing and late treatment) was developed as part of the PLHIV Stigma Index implementaion, and 87 respondents were also involved as participants in this study. The addittional study was in response to a need identified by five PLHIV organisations in the region (in Estonia, Moldova, Poland, Turkey Ukraine) to look at the barriers that resulted in late testing and late treatment[15].

Confidentiality: In order to maintain participants' confidentiality the questionnaire was anonymous, and no information was collected which could be used to identify people. Participants were informed both verbally and on the informed consent form about their right to refuse to participate or to interrupt their participation at any stage of the study without any consequences.

Data collectors: The eight (8) interviewers were all members/volunteers of the Estonian Network of PLHIV.

Data analysis: The results of the survey were processed using data-processing programme PASW Statistics 18.0.

Ethical considerations: The protocol of the study was approved by Tallinn Medical Research Ethics Committee.

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[14] For more information go to www.stigmaindex.org

[15] The full cross country report 'Late Testing, Late Treatment' can be accessed at www.stigma.index.org

Study limitations

Efforts were taken in the survey design and interviewing phases to include the broadest range of people living with HIV possible within funding and time constraints. Therefore, the results of this survey, while indicative of the range of experiences of people living with HIV in Estonia, cannot be generalized to all people living with HIV in Estonia.

In particular, people living with HIV who do not know their status or who have not accessed any treatment, care or support services were inaccessible to the researchers and are not included in this study. Their experiences may differ from those of the survey respondents in meaningful ways.

In addition, the sample included very small numbers of people from some key populations, which made it impossible to provide meaningful statistical analysis regarding these populations. Not enough respondents were identified who categorized themselves as men who have sex with men, transgender people, refugees or asylum seekers, internally displaced persons, members of indigenous groups, or migrant workers to provide analyses of these populations. Work will be done by the Estonian network to reach out to these populations in further studies.

What is in this report?

This report follows the content of the questionnaire and is divided into five sections:

- **Section 1:** General information about the respondent and her/his household.
- **Section 2:** Reported experiences of HIV-related stigma and discrimination; internal stigma (felt or internalised stigma); the protection of the rights of PLHIV through law, policy and/or practice; and effecting change at household and community levels in responding to stigma and discrimination.
- **Section 3:** Experience of testing, disclosure, treatment and having children.
- **Section 4:** Qualitative questions to identify barriers faced by people when accessing HIV testing and, after a HIV-positive diagnosis, treatment and care.
- **Section 5:** Qualitative questions on access to health services, information disclosure and breaches of confidentiality, access to ART, and children of HIV-positive parents.

Conclusions and recommendations are then presented.

Section 1:
Background characteristics and household composition

Almost two-thirds of the respondents were men (63%, n=189) and almost two-fifths were women (37%, n=111). 80% of the respondents were between the ages of 25-39 with a further 13% between 20 and 24 years old. Only 1% of respondents were under age 20 and another 1% was over age 49.

Chart 2: Respondents' age distribution by gender

Chart 2 disaggregates the respondents by age and gender. Both interviewees aged 15 to 19 were women, and both of the respondents more than 50 years old were men.

Among respondents aged 20-24 were more women than men. In the three other age groups there were more men.

Length of time living with HIV

Chart 3: Time living with HIV

Chart 3 outlines the length of time respondents had been living with HIV, while **Chart 4** disaggregates this data by gender.

One female respondent had lived with HIV for 15 years or more (0.3%).

The largest percentage of respondents, 42% (n=127), had been living with HIV for

5-9 years, of whom 67% were men and 33% women. 23% (n=69) of respondents had been living with HIV for 10-14 years of whom 70% were men and 30% women, while 28% (n=82) had been living with HIV for 1-4 years of whom 54% were men and 46% women

Chart 4: Time living with HIV

Relationship status

Chart 5: Current relationship status

Chart 5 shows that almost two-fifths of respondents (38%, n=113) lived with a spouse or partner; 17% (n=52) had a spouse or partner but did not live with her/him; while 45% (n=135) were single (unmarried, divorced or widowed).

Sexual activity and relationship status

74% of respondents report that they were currently sexually active with 26% stating that they were not. **Chart 6** shows the sexual activity of respondents by their relationship status. 64% (n=16) of divorced/separated people, 55% (n=58) of singles, and 40% (n=2) of widows/widowers are sexually active. 92% (n=104) of those who live together with someone are sexually active; while of those with a spouse or partner but who are temporarily away from home, 80% (n=12) are sexually active.

Chart 6: Sexual activity and present relationship status

Of those respondents currently in a relationship (n=165), one third (35%) of the relationships have lasted for 1-4 years, approximately another third (32%) were less than a year old; while 27% reported being in a relationships of 5-9 years. There was no significant difference by gender of the respondents in the duration of the current relationship.

Physical disability

Thirty-one respondents (10%) reported a physical disability of any kind (not including general ill health related to HIV). 88% indicated that they did not have such a physical disability and 2% did not answer the question.

Education

Respondents' educational levels were generally low, with 6% (n=17) reporting no formal education and a further 33% (n=100) reporting primary level education. Secondary school education was the most frequently reported education level of respondents (37%, n=110) with nearly one quarter (24%, n=72) having a tertiary level education.

Employment status

66% (n=199) of respondents were unemployed, 26% (n=88) are employed either part- or full-time with an additional 2% (n=5) describing themselves as self-employed, and the remaining 6% (n=18) undertaking casual work. There are relatively more women than men among the unemployed (75%, n=83 compared to 61%, n=116), and more men among full time and part time employees (18% (n=33) and 13% (n=25)) than women. (11% (n=12) and 7% (n=8)).

Younger respondents (under the age of 30) were the most likely to be unemployed or employed part-time or undertaking casual labour with 20-24 years old persons relatively most often unemployed (78%, n=31).

Estonia

Number of persons who live in respondents' households

On average, 2.2 people lived together with the respondent at the time of the survey; with 8% (n=25) indicating living alone.

Children at age 0-14: 37% (n=110) of respondents indicated that they have children who are aged 14 or under living in their household. Of these, the majority had one child of this age (68%, n=75) while smaller numbers indicated that they had two or three children of this age (26%, n=29, and 6%, n=6, respectively). There were no significant differences between male and female respondents for this question.

Adolescents aged 15-19: 16 (5%) respondents reported that they had either one or two children aged 15-19 living in their household with no respondent indicating more than two adolescents. There were no significant differences in responses by gender.

Two respondents, one male and one female with both living in Kohtla-Järve, indicated that they each had one child or youth who had been orphaned due to AIDS and was living in their household.

Place of residency

3% of respondents live in villages, 14% in smaller cities and 83% in large cities.

Key populations

In terms of key populations (*riskirüh:* 'risk group - Estonian), the largest group of respondents was people who use drugs (78%, n=232) with over half (51%, n=151) being former or current prisoners, and 43% (n=129) identifying as people who use drugs and as prisoners or former prisoners.

There were also smaller groups of respondents from other key populations, including 5% who identified as gay or lesbian or as sex workers. Very few respondents identified as men who have sex with men, refugees or asylum seekers, internally displaced people, or members of indigenous groups. No respondents identified as transgender people or as migrant workers.

People who use drugs

Among the respondents there were 232 (78%) who identified as current or former injecting drug users, of whom:

- 68% were men and 32% were women.
- Typically they had lived with HIV for 5-9 years (42%);

- 56% live with a partner, 34% are single, 7% divorced, and 2% are widows/widowers. The duration of the relationship is 1-4 years in 35% of the cases, up to a year in 29%, and 5-9 years in 28% of the cases.
- 38% have primary education, 36% have secondary education; while approximately one fifth (21%) has acquired a vocational, 'technical college' or university degree.
- 69% are unemployed, 24% have part- or full-time labour, and 7% undertake casual labour.

Prisoners

Among the respondents there were 151 prisoners (50%) of whom:

- 43% has lived with HIV 5-9 years, 33% 10-14 years.
- 36% have basic education and 34% secondary education. 23% have vocational secondary or higher education.
- 73% are unemployed. The rest of them have part- or full-time jobs.

Sex workers

There were 16 female respondents (5%) who categorized themselves as sex workers, of whom:

- 3 defined themselves as lesbians, 14 as current or former people who use drugs, and 7 as current or former prisoners.
- 7 have children who are up to 14 years old.
- 11 are currently sexually active.
- 1 has no formal education, 5 have primary school level education, 6 have secondary school level, and 4 have vocational or higher education.
- One person has lived with HIV for about a year, 6 people 1-4 years, 7 people 5-9 years, and 2 people 10-14 years.

Gay or lesbian

There were 15 people (5%) who categorized themselves as gay (4) or lesbian (11), of whom:

- 5 identified as current or former prisoners, 9 identified as current or former people who use drugs, 3 of the women identified as sex workers, and 2 of the men also identified as men who have sex with men.
- 4 live together with children aged up to 14.
- 10 are currently sexually active.
- 4 have no formal education, 3 have primary school level education, 4 have secondary school level, and 4 have vocational or higher education.
- 2 people have lived with HIV for less than one year, 4 people1-4 years, 5 people 5-9 years, and 4 people 10-14 years.

Economic status

Of 297 respondents, 3 people indicated they had no income. The median monthly income was 6000 EEK with the mean monthly income being 7881 EEK (**Table 1**). The median annual income is therefore 72 000 EEK ($ 6,408). 35% (n=104) of respondents are lower income, 33% (n=100) middle income, and 31% (n=93) higher income[16].

Table 1: Respondents' monthly income in EEK and USA dollars and their annual income in USA dollars

Monthly income in Estonian kroons	%	Monthly income in US dollars	Annual income in US dollars
1 000 or less	5% (n=14)	88$ or less	1 067$ or less
1 001 – 3 000	16% (n=48)	89 – 267$	1 068 – 3 200$
3 001 – 5 000	25% (n=73)	268 – 444$	3 201 – 5 333$
5 001 – 7 000	16% (n=47)	445 – 622$	5 334 – 7 467$
7 001 – 9 000	7% (n=22)	623 – 799$	7 476 – 9 588$
9 001 – 11 000	13% (n=39)	800 – 977$	9 589 – 11 724$
11 001 - 20 000	16% (n=47)	978 – 1 776$	11 725 – 21 312$
More than 20 000	2% (n=7)	More than 1 776$	More than 21 312$

** Calculations are based on exchange rate $ 1 USD = 11.25 EEK Respondents were divided into three groups based on income for further analysis. Note that these income groups are not based on average Estonian levels of income but on the averages within the sample itself.*

There were relatively more women than men who reported lower levels of income. Regional differences were clearly distinguishable. In Tartu, compared to the three other cities, there were many more respondents who reported average or high incomes (88% compared to 40% to 67%). 56% of respondents reported lower income in Kohtla-Järve. However these differences may well have no significance due to the sampling method employed

Among the respondents who belonged to key populations, the only meaningful difference in income level was for men who were current or former prisoners. Of these men, 34% reported being in the lowest income group, compared to 25% of men who had never been

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[16] Income categories were divided as follows:

- Lower income - (0 - 75% from the median) 0 to 4600 EEK per month
- Average income - (76% - 150% from the median) 4601 to 9000 EEK per month
- Higher income - (151% over the median) More than 9000 EEK per month

prisoners. Notably, these percentages for male respondents were still better than for female respondents, as 42% of female respondents overall and 43% of women, who were current or former prisoners, reported the lowest income levels.

Chart 7 shows that the greatest percentage of respondents with the lowest income is in households of 1-2 people (46%), significantly above the average of 35%, with a quarter of respondents in 3-5 member households and 35% in 6 or more member households with the lowest income. These households would, presumably, also require less income. There is a large jump in the percentage of households with average and higher income among households with 3-5 members (75% combined) and 6 or more members (65% combined).

Chart 7: Number of household members by income group

Food security and insecurity

In response to a question about in the last month, how many days has any member of the respondent's household not had enough food to eat; 54% (n=163) answered none; while 22% (n=67) had felt hungry at least once, and seventy respondents (23%) did not answer this question. For the 67 people, who had felt hungry at least once, the median number of days without enough food was 7. The maximum duration for which respondents had felt hungry was 30 days (2 respondents); and 3 respondents reported being without food for 20 days in the last month.

In order to more closely analyze which groups reported the most food shortages, the data were grouped into three categories:

- 'No shortage of food' were grouped those who said that the household members had not felt hungry during the last month.

- 'Moderate shortage of food' means at least one member of the household did not have enough to eat 1-2 times during last month.
- 'Serious shortage of food' means that there were 3 or more days during last month in which at least one member of the respondent's household did not have enough to eat.

As shown in **Chart 8**, while 71% of respondents report no food shortage; 24% reported 'severe food shortage'. There were clear differences between the four cities. For example, respondents from Kohtla-Järve (71%) and Narva (48%) were significantly more likely to report serious food shortages (p=.000) than Narva (7%) and Tallinn (3%).

Overall, female respondents (33%) reported more days without enough food than male respondents (26%). When the results were examined by sex and by city, women reported more food shortages than men in every city (with women’s food shortages ranging from 8% to 80% and men’s food shortages ranging from 3% to 57%).

Chart 8: Food shortages in the last month by sex and location of the respondents

Chart 9 shows data concerning food shortages faced by key population in the last month. Overall 29% reported moderate and serious food shortages, with high levels of food shortages reported by people who use drugs (32%) and prisoners (27%).

Chart 9: Food shortages faced by key populations in the last month

Data was disaggregated by respondents' language group: Estonian or Russian. Most respondents were Russian speakers (90%, n=271) with 29 Estonian speakers (10%). Responses differed, sometimes significantly, between the two language groups.

- Estonian speakers were more likely to be male (83% to 61%) and more recently diagnosed (59% to 32% were diagnosed in the last 4 years).
- Russian speakers were more likely to be, or have been, people who use drugs and prisoners; report much higher levels of food insecurity, e.g. 27% of Russian speakers, compared to 7% of Estonian speakers, reporting three or more days in which their household did not have enough to eat in the last month.

The characteristics of the respondents for each group are shown in **Table 2**.

Table 2: Characteristics of respondents disaggregated by preferred language

	Russian language	Estonian language	Sample Total
Percent of total respondents	90% (n=271)	10% (n=29)	100% (n=300)
Male	61% (n=165)	83% (n=24)	63% (n=189)
Living with HIV for 4 years or less	32% (n=86)	59% (n=17)	34% (n=103)
Gay or lesbian	4% (n=12)	10% (n=3)	5% (n=15)
Sex worker	6% (n=15)	3% (n=1)	5% (n=16)
Injecting drug user	81% (n=220)	41% (n=12)	77% (n=232)
Prisoner	54% (n=146)	17% (n=5)	50% (n=151)
Serious food shortages in the last month	27% (n=54)	7% (n=2)	24% (n=56)

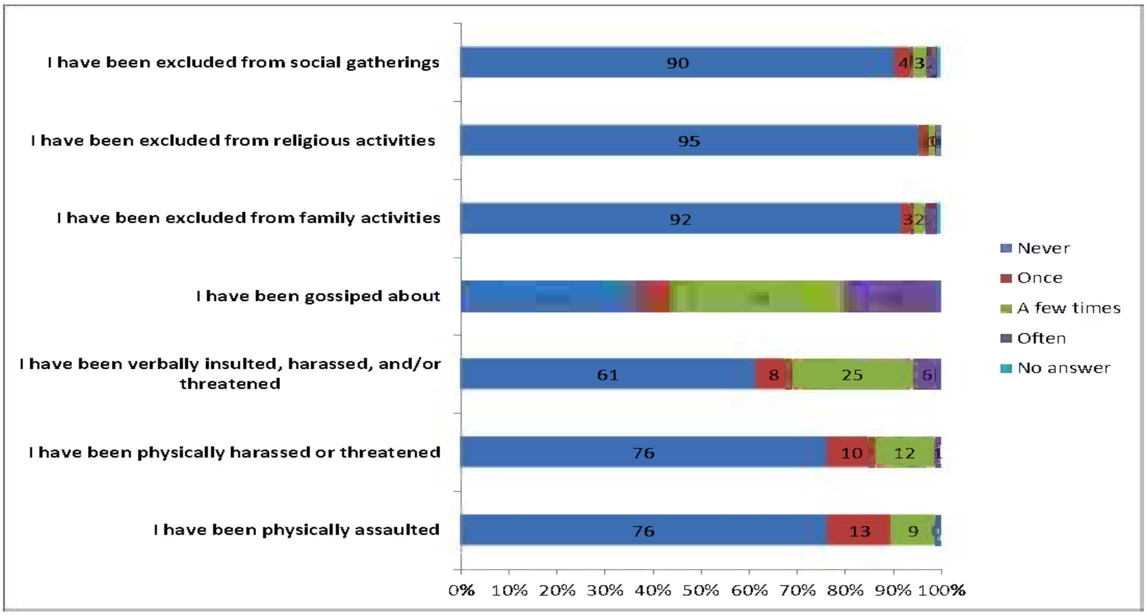
Section 2: Experience of stigma and discrimination

This Section comprises five sub-sections: experiences of HIV-related stigma and discrimination; access to work and health and education services; internalised stigma; the protection of the rights of people living with HIV through the law, policy or practice; and effecting change.

2.1 Experience of HIV-related stigma and discrimination

Respondents were asked about their experiences of stigma and discrimination in the previous 12 months (**Chart 10**). The majority of respondents (63%) reported that they had been gossiped about. Significant percentages of respondents reported having been verbally insulted/harassed/threatened (39%); physically assaulted or threatened (24%); and/or physically assaulted (22%) at least once in the last year. In addition, between 5% and 10% of respondents reported exclusion from religious activities, family activities and/or social gatherings over the past 12 months.

Chart 10: Stigmatization and discrimination experienced over the past 12 months, all respondents



Respondents were also asked to indicate the reasons for being stigmatised and discriminated against during last 12 months (**Chart 11**). Of 183 respondents who had been gossiped about, 39% (n=73) indicated that it occurred, in whole or in part, because of their HIV-positive status[17]; while 52% indicated that it was for another reason. In addition, 31% indicated being insulted/harassed/threatened, physically assaulted or threatened (12%), and/or physically assaulted (10%) during the last 12 months in whole or in part, because of their HIV-positive status.

Chart 11: Reasons for stigmatization and discrimination against those respondents subjected to it during last 12 months

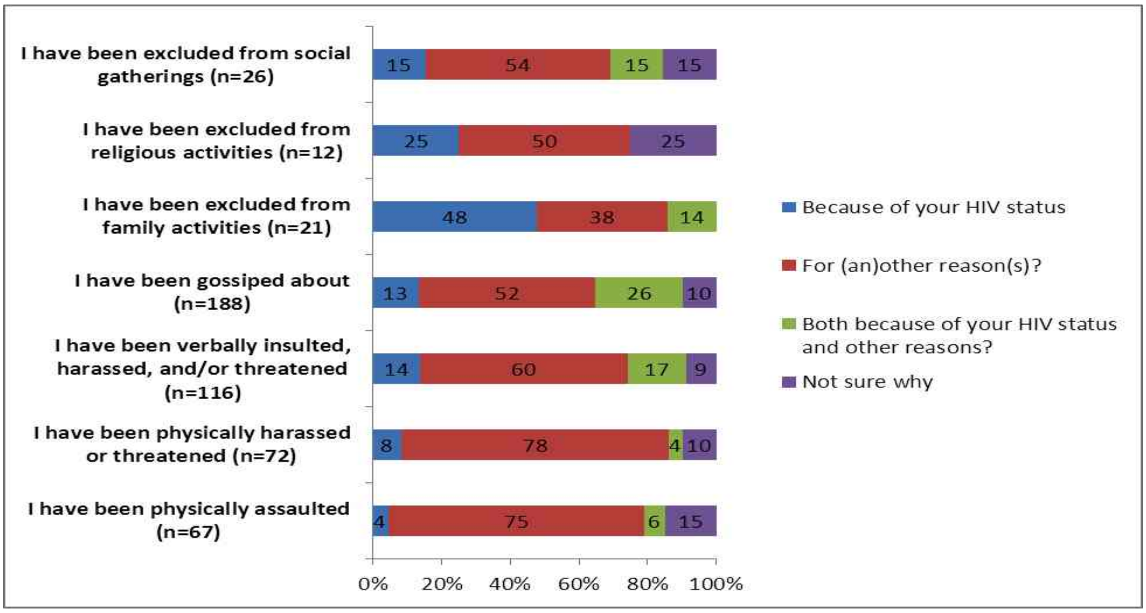


Table 3 shows that being gossiped about 'often' was more frequently reported by:

- Women than men (e.g. 31% versus 14%).
- Russian speakers than Estonian speakers (21% versus 7%).
- People with lower income than those with average or higher income (30% versus 16% and 13%, respectively).

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[17] In order to determine whether mistreatment was due to HIV status, two responses were combined: 'because of HIV-positive status' and 'HIV-positive status and other reasons as well'

Table 3: Aware of being gossiped about in the last 12 months[18]

	Never	Once	A few times	Often	Total
SEX					
Men	43% (n=80)	5% (n=10)	38% (n=72)	14% (n=26)	100% (n=188)
Women	28% (n=31)	9% (n=10)	32% (n=36)	31% (n=34)	100% (n=111)
AGE					
15-19 years	50% (n=1)		50% (n=1)		100% (n=2)
20-24 years	50% (n=20)		30% (n=12)	20% (n=8)	100% (n=40)
25-29 years	31% (n=37)	8% (n=9)	38% (n=45)	23% (n=27)	100% (n=118)
30-39 years	37% (n=45)	8% (n=10)	36% (n=43)	19% (n=23)	100% (n=121)
40-49 years	50% (n=8)	6% (n=1)	38% (n=6)	6% (n=1)	100% (n=16)
50 years and above			50% (n=1)	50% (n=1)	100% (n=2)

Verbally insulted/harassed/threatened

Table 4 shows that being verbally insulted/harassed/threatened "a few times" or "often" was more frequently reported by:

- Those aged 20 to 24 years old (53% versus 0% to 32% in other age groups).
- People with lower income than those with average or higher income (41% compared to 27% and 25%, respectively).
- Russian speakers than Estonian speakers (34% versus 10%).
- People who use or used drugs (35% compared to 19% with no history of drug use).
- Sex workers (50% versus 30% who were not sex workers).

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[18] The results for subgroups that have fewer than 5 representatives are marked with grey font.

Table 4: Being insulted/harassed/threatened in the last 12 months[19]

	Never	Once	A few times	Often	Total
SEX					
Men	65% (n=122)	7% (n=14)	23% (n=43)	5% (n=10)	100% (n=189)
Women	56% (n=62)	8% (n=9)	19% (n=32)	7% (n=8)	100% (n=111)
AGE					
15-19 years	0% (n=0)	0% (n=0)	100% (n=2)	0% (n=0)	100% (n=2)
20-24 years	45% (n=18)	3% (n=1)	45% (n=18)	8% (n=3)	100% (n=40)
25-29 years	57% (n=68)	11% (n=13)	25% (n=30)	7% (n=8)	100% (n=119)
30-39 years	71% (n=86)	6% (n=7)	18% (n=22)	5% (n=6)	100% (n=121)
40-49 years	69% (n=11)	13% (n=2)	19% (n=3)	0% (n=0)	100% (n=16)
50 years and above	50% (n=1)	0% (n=0)	0% (n=0)	50% (n=1)	100% (n=2)
TIME LIVING WITH HIV					
0-1 year	60% (n=12)	5% (n=1)	35% (n=7)	0% (n=0)	100% (n=20)
1-4 years	54% (n=45)	7% (n=6)	30% (n=25)	8% (n=7)	100% (n=83)
5-9 years	68% (n=86)	7% (n=9)	20% (n=25)	6% (n=7)	100% (n=127)
10-14 years	58% (n=40)	10% (n=7)	26% (n=18)	6% (n=4)	100% (n=69)
15+ years	100% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)	100% (n=1)
KEY POPULATION					
Gay or lesbian	60% (n=9)	7% (n=1)	20% (n=3)	13% (n=2)	100% (n=15)
Sex worker	50% (n=8)	0% (n=0)	50% (n=9)	0% (n=0)	100% (n=16)
Injecting drug user	59% (n=136)	7% (n=16)	29% (n=67)	6% (n=13)	100% (n=232)
Prisoner	60% (n=90)	7% (n=10)	25% (n=75)	6% (n=18)	100% (n=151)
LANGUAGE					
Russian (n=271)	59% (n=159)	8% (n=22)	27% (n=72)	7% (n=18)	100% (n=271)
Estonian (n=28)	86% (n=25)	3% (n=1)	10% (n=3)	0% (n=0)	100% (n=29)
EDUCATION					
No formal education	47% (n=8)	12% (n=2)	35% (n=6)	6% (n=1)	100% (n=17)
Primary school	60% (n=60)	5% (n=5)	30% (n=30)	5% (n=5)	100% (n=100)
Secondary school	69% (n=76)	7% (n=8)	19% (n=21)	5% (n=5)	100% (n=110)
Technical college/university	56% (n=40)	11% (n=8)	25% (n=18)	8% (n=6)	100% (n=72)
INCOME GROUP					
Lower income	53% (n=55)	7% (n=7)	27% (n=28)	14% (n=14)	100% (n=104)
Average income	63% (n=63)	10% (n=10)	26% (n=26)	1% (n=1)	100% (n=100)
Higher income	69% (n=64)	7% (n=6)	22% (n=20)	3% (n=3)	100% (n=93)

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[19] The results for subgroups that have fewer than 5 representatives are marked with grey font.

Physical harassment and threats of violence

Table 5 shows that 90% (n=26) of Estonian speaking respondents compared to 75% (n=203) of Russian speakers reported never being physically harassed or threatened. Furthermore, Respondents aged 25 to 29 years old were more likely to report physical harassment or threats had occurred "a few times" or "often" in the last 12 months (20% (n=23) versus between 8% and 13% in other age groups).

Table 5: Physical harassment and threats of violence in the last 12 months [20]

	Never	Once	A few times	Often	Total
SEX					
Men	76% (n=143)	11% (n=21)	12% (n=23)	1% (n=2)	100% (n=189)
Women	78% (n=86)	8% (n=9)	13% (n=14)	2% (n=2)	100% (n=111)
AGE					
15-19 years	0% (n=0)	50% (n=1)	50% (n=1)	0% (n=0)	100% (n=2)
20-24 years	70% (n=28)	23% (n=9)	8% (n=3)	0% (n=0)	100% (n=40)
25-29 years	72% (n=86)	8% (n=10)	17% (n=20)	3% (n=3)	100% (n=119)
30-39 years	85% (n=103)	6% (n=7)	9% (n=11)	0% (n=0)	100% (n=121)
40-49 years	69% (n=11)	19% (n=3)	13% (n=2)	0% (n=0)	100% (n=16)
50 years and above	50% (n=1)	0% (n=0)	0% (n=0)	50% (n=1)	100% (n=2)
TIME LIVING WITH HIV					
0-1 year	75% (n=15)	10% (n=2)	15% (n=3)	0% (n=0)	100% (n=20)
1-4 years	70% (n=58)	16% (n=13)	35% (n=29)	12% (n=10)	100% (n=83)
5-9 years	80% (n=102)	7% (n=9)	12% (n=15)	1% (n=1)	100% (n=127)
10-14 years	77% (n=53)	9% (n=6)	13% (n=9)	1% (n=1)	100% (n=69)
15+ years	100% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)	100% (n=1)
KEY POPULATION					
Gay or lesbian	73% (n=11)	0% (n=0)	20% (n=3)	7% (n=1)	100% (n=15)
Sex worker	75% (n=12)	6% (n=1)	19% (n=3)	0% (n=0)	100% (n=16)
Injecting drug user	75% (n=173)	11% (n=25)	13% (n=31)	1% (n=3)	100% (n=232)
Prisoner	76% (n=115)	11% (n=16)	13% (n=19)	1% (n=1)	100% (n=151)
LANGUAGE					
Russian	75% (n=203)	10% (n=28)	13% (n=36)	2% (n=4)	100% (n=271)
Estonian	90% (n=26)	7% (n=2)	3% (n=1)	0% (n=0)	100% (n=29)
EDUCATION					
No formal education	65% (n=11)	12% (n=2)	18% (n=3)	6% (n=1)	100% (n=17)
Primary school	72% (n=72)	16% (n=16)	11% (n=11)	1% (n=1)	100% (n=100)
Secondary school	83% (n=91)	6% (n=6)	11% (n=12)	1% (n=1)	100% (n=110)
Technical college/university	76% (n=55)	8% (n=6)	15% (n=11)	0% (n=0)	100% (n=72)
INCOME GROUP					
Lower income	74% (n=77)	8% (n=8)	15% (n=16)	3% (n=3)	100% (n=104)
Average income	77% (n=77)	12% (n=12)	10% (n=10)	1% (n=1)	100% (n=100)
Higher income	79% (n=73)	10% (n=9)	12% (n=11)	0% (n=0)	100% (n=93)

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[20] The results for subgroups that have fewer than 5 representatives are marked with grey font.

Physical assault

Respondents with no formal education (36%, n=6) or a primary school education (30%, n=30) were significantly more likely than other respondents (e.g. 14% (n=15) with secondary education and 23% (n=16) of those with tertiary education) to report that they were physically assaulted in the last 12 months (**Table 6**).

Table 6: Physical assault in the last 12 months [21]

	Never	Once	A few times	Often	Total
SEX					
Men	77% (n=144)	15% (n=27)	8% (n=14)	1% (n=1)	100% (n=186)
Women	77% (n=85)	12% (n=13)	12% (n=13)	0% (n=0)	100% (n=111)
AGE					
15-19 years	100% (n=2)	0% (n=0)	0% (n=0)	0% (n=0)	100% (n=2)
20-24 years	80% (n=32)	15% (n=6)	5% (n=2)	0% (n=0)	100% (n=40)
25-29 years	68% (n=80)	15% (n=17)	16% (n=19)	1% (n=1)	100% (n=117)
30-39 years	83% (n=100)	12% (n=15)	5% (n=6)	0% (n=0)	100% (n=121)
40-49 years	93% (n=14)	7% (n=1)	0% (n=0)	0% (n=0)	100% (n=15)
50 years and above	50% (n=1)	50% (n=1)	0% (n=0)	0% (n=0)	100% (n=2)
TIME LIVING WITH HIV					
0-1 year	85% (n=17)	5% (n=1)	10% (n=2)	0% (n=0)	100% (n=20)
1-4 years	72% (n=59)	16% (n=13)	12% (n=10)	0% (n=0)	100% (n=82)
5-9 years	79% (n=99)	14% (n=18)	6% (n=8)	1% (n=1)	100% (n=126)
10-14 years	78% (n=53)	12% (n=8)	10% (n=7)	0% (n=0)	100% (n=68)
15+ years	100% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)	100% (n=1)
KEY POPULATION					
Gay or lesbian	57% (n=8)	21% (n=3)	21% (n=3)	0% (n=0)	100% (n=14)
Sex worker	69% (n=11)	6% (n=1)	25% (n=4)	0% (n=0)	100% (n=16)
Injecting drug user	75% (n=172)	14% (n=33)	10% (n=24)	0% (n=1)	100% (n=232)
Prisoner	74% (n=110)	14% (n=20)	12% (n=18)	0% (n=0)	100% (n=148)
LANGUAGE					
Russian	76% (n=206)	14% (n=38)	10% (n=26)	0% (n=1)	100% (n=271)
Estonian	89% (n=23)	8% (n=2)	4% (n=1)	0% (n=0)	100% (n=26)
EDUCATION					
No formal education	65% (n=11)	24% (n=4)	12% (n=2)	0% (n=0)	100% (n=17)
Primary school	70% (n=70)	14% (n=14)	16% (n=16)	0% (n=0)	100% (n=100)
Secondary school	86% (n=94)	8% (n=9)	5% (n=5)	1% (n=1)	100% (n=109)
Technical college/university	77% (n=54)	17% (n=12)	6% (n=4)	0% (n=0)	100% (n=70)
INCOME GROUP					
Lower income	76% (n=79)	14% (n=14)	10% (n=10)	1% (n=1)	100% (n=104)
Average income	77% (n=75)	13% (n=13)	10% (n=10)	0% (n=0)	100% (n=98)
Higher income	79% (n=73)	13% (n=12)	8% (n=7)	0% (n=0)	100% (n=92)

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[21] The results for subgroups that have fewer than 5 representatives are marked with grey font.

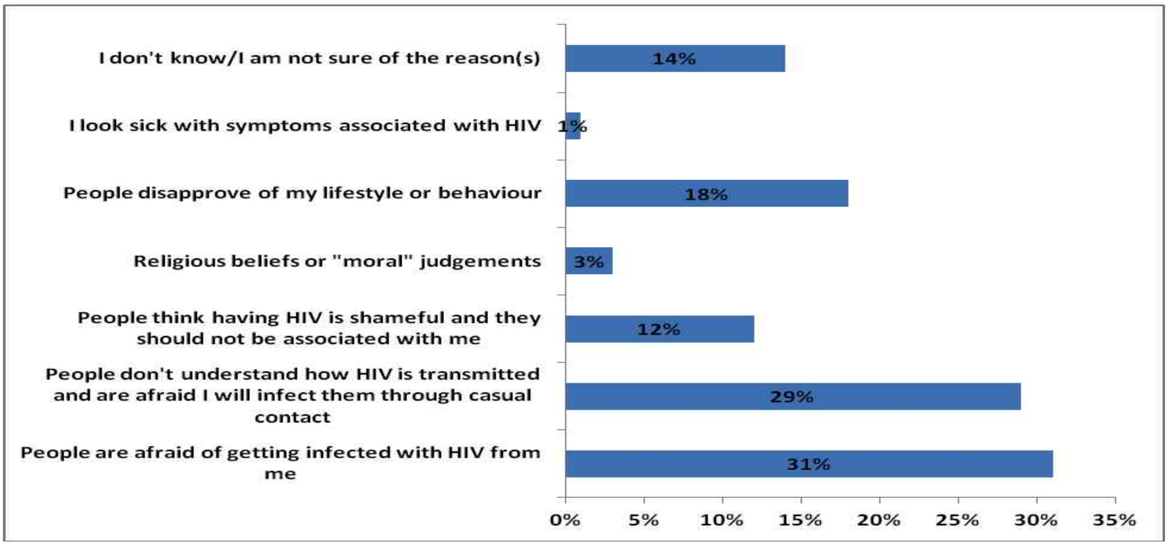
Of those respondents who had suffered physical assault, in 42% of the cases (n=28) the person who used physical violence was unknown; however, in 58% of instances (n=38) the respondent knew the person, including in nearly a quarter of the cases (24%, n=16) in which a spouse or partner was the perpetrator (**Chart 12**)

Chart 12: Perpetrators of violence, n = 66

HIV-positive people’s experience of stigmatization and discrimination

Respondents who had experienced some form of HIV-related stigma and/or discrimination in the last 12 months, were asked why they thought this was (**Chart 13**). (29%, n=87) of respondents feel that the HIV-related stigma and/or discrimination they have faced is due to people not understanding how HIV is transmitted/ afraid of getting infected by casual contact, with another 31% (n=93) citing other people’s fears of infection by casual contact. Nearly one in five (18%, n=54) cited people disapproving of their lifestyle or behaviour.

Chart 13: Reasons why HIV-positive respondents experienced discrimination and stigmatization



2.2 Access to work and health and education services

This sub-section focuses on the extent to which access to accommodation, work, health and education services were influenced by respondents' HIV positive-status.

Accommodation

Respondents were asked about being forced to change residence or their inability to secure rental accommodation in the previous 12 months (**Table 7**). While approximately 74% (n=217) had not experienced this form of discrimination, over one quarter (26%, n= 78) had been forced to change residency/refused accommodation. Eight of these respondents (10%) thought that the reason was HIV-positive status, in whole or in part. 81% (n=63) said that it was for another reason and 9% (n=7) were unsure why.

Table 7: Loss of housing

	Frequency	%
Never	217	74
Once	26	9
A few times	46	16
Often	6	2
TOTAL	**295**	**100**

Work

Of 129 respondents, 29% (n=38) reported having lost a job or another source of income, while 71% (n=91) reported that this had not happened to them in the last 12 months (**Table 8**). Four (4) respondents, 11%, believe that it happened because of their HIV-positive status, in whole or in part. Of these, two said job loss was due to discrimination by their employer or co-workers, one respondent indicated that it was due to poor health, and one respondent indicated that it was for another reason.

Table 8: Lost a job or another source of income In the last 12 months

	Frequency	%
Never	91	71
Once	15	12
A few times	20	15
Often	3	2
TOTAL	129	100

Table 9 shows that 7% (n=9) of respondents reported having been refused employment or work opportunities on account of their HIV status in the last 12 monthsTwo (2%) respondents believed that their job description or the nature of their work changed, or they had been refused promotion, as a result of their HIV status in the last 12 months.

Table 9: Refusal of employment because of HIV status

	Frequency	%
Yes	9	7
No	120	93
TOTAL	**129**	**100**

Education

Of 298 respondents, only 11 (4%) indicated that they had been dismissed, suspended, or prevented from attending an educational institution in the previous 12 months (**Table 10**).

Table 10: Dismissal, suspension or prevented from attending an educational institution because of your HIV status in the last 12 months

	Frequency	%
Never	270	91
Once	8	3
A few times	2	1
Often	1	0
Not applicable	17	6
TOTAL	**298**	**100**

Table 11 shows that from a sample of 181 respondents, only 4 (1%) had experienced that their children have been dismissed, suspended or prevented from attending an educational institution because of the respondent's HIV status during the last 12 months.

Table 11: Dismissal, suspension or prevention of children from an educational institution because of the respondent's HIV status in the previous 12 months

	Frequency	%
Never	177	59
Once	3	1
A few times	1	0
Often	0	0
Not applicable	118	40
TOTAL	299	100

Health Services

Table 12 shows that 25 respondents (8%) report being denied health services, including dental care, at least once in the last 12 months. Of these, six respondents (2%) indicated that care was denied a few times and three (1%) reported that health care had been denied often over the last year.

Table 12: Denial of health services, including dental care, because of your HIV status in the last 12 months

	Frequency	%
Never	270	90
Once	16	5
A few times	6	2
Often	3	1
Not applicable	5	2
TOTAL	300	100

All 300 respondents were also asked whether they had experienced challenges in accessing family planning and other sexual and reproductive health services in the last 12 months. Findings included:

- Some 4% (n=12) of respondents have been refused family planning services during the last 12 months; of these, half were women (n=6) and half were men (n=6) with one (1) aged 20-24, six (6) aged 25-29 and five (5) aged 30-39.
- Some 2% (n=6) of respondents had been denied sexual and reproductive health services during the last 12 months; half of whom were women (n=3) and half were men (n=3).

2.3 Internal stigma and fears

This sub-section focuses on identifying forms of internalised stigma among respondents.

Feelings

The results presented in the chart below show that internal stigma was prevalent among respondents in the last 12 months. Over 60% (n=180) feel guilt, 57% (n=169) blame themselves, 42% (n=126) feel ashamed, and 33% (n = 100) have low self esteem. Furthermore, 10% of respondents reported feeling suicidal.

Chart 14: Feelings experienced during last 12 months

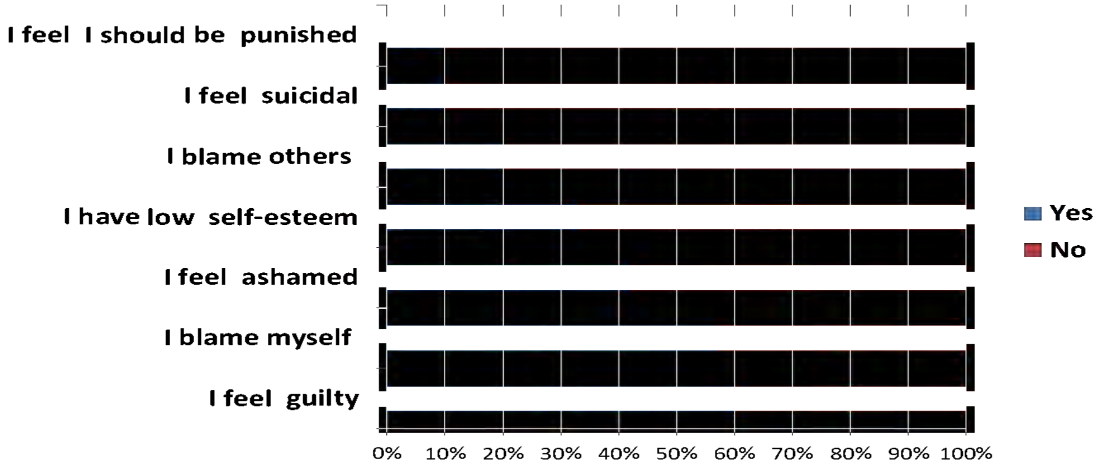


Table 13 describes experienced feelings by sex, language and key population. Women reported that they felt ashamed more often than men (47% to 39%), have more suicidal thoughts than men (15% to 7%). Furthermore, those respondents from the Estonian community in comparison to the Russian speaking community reported higher levels of shame (62% to 40%) and guilt (79% to 58%) as well as and lower self-esteem (48% to 31%) than people who belonged to the Russian community.

Table 13: Experienced feelings disaggregated by sex, language and key population

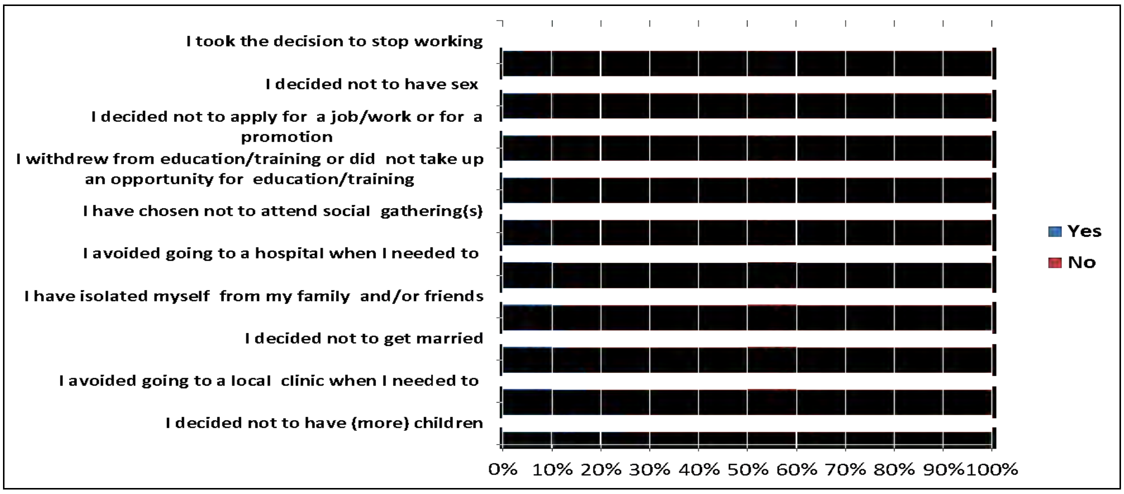
	Men	Women	Russian speaker	Estonian speaker	Gay or Lesbian	Sex worker	Injecting drug user	Prisoner	TOTAL
I feel ashamed	39% (n=74)	47% (n=52)	40% (n=108)	62% (n=18)	68% (n=10)	50% (n=8)	40% (n=93)	34% (n=52)	42% (n=299)
I feel guilty	62% (n=117)	57% (n=63)	58% (n=157)	79% (n=23)	73% (n=11)	56% (n=9)	58% (n=134)	58% (n=87)	60% (n=298)
I blame myself	59% (n=110)	53% (n=59)	56% (n=152)	61% (n=17)	53% (n=8)	56% (n=9)	58% (n=134)	58% (n=87)	57% (n=298)
I blame others	18% (n=33)	23% (n=25)	20% (n=53)	18% (n=5)	27% (n=4)	25% (n=4)	17% (n=40)	15% (n=22*	20% (n=296)
I have low self-esteem	31% (n=59)	35% (n=39)	31% (n=84)	48% (n=14)	60% (n=9)	50% (n=8)	29% (n=68)	27% (n=41)	33% (n=299)
I feel I should be punished	9% (n=16)	12% (n=13)	10% (n=27)	7% (n=2)	13% (n=2)	0% (n=0)	10% (n=24)	8% (n=12)	10% (n=298)
I feel suicidal	7% (n=13)	15% (n=17)	10% (n=28)	7% (n=2)	13% (n=2)	13% (n=2)	12% (n=27)	11% (n=17)	10% (n=299)

Decisions, resignations, avoidance

Chart 15 shows respondents' decisions not to engage in some activities because of their HIV-positive status. The most frequently cited reaction, by 25% of respondents (n=74) was the decision not to have (more) children. Furthermore, 13% (n=39) opted not to marry; and 12% (n=35) isolated themselves from friends and relatives.

Internal stigma also affects access to health care: 17% (n=51) avoided going to a local clinic when they needed care, and 11% (n=34) avoided going to hospital. In relation to study and employment: 8% (n=23) withdrew from education or training, 7% (n=21) decided not to apply for a job or a promotion because of their HIV status and 4% (n=13) gave up their job.

Chart 15: Decisions, resignations and avoidances



Fears

Respondents' level of fear of being gossiped about, verbally insulted, physically harassed and/or threatened, and physically assaulted is shown in **Chart 16**. Overall, 41% of respondents feared being gossiped about; significantly higher levels of fear than verbal insult (29%), physical harassment and/or threat (20%), and physical assault (17%).

Chart 16: Fear of gossip, insults, harassment, and assault in the last 12 months, n=299

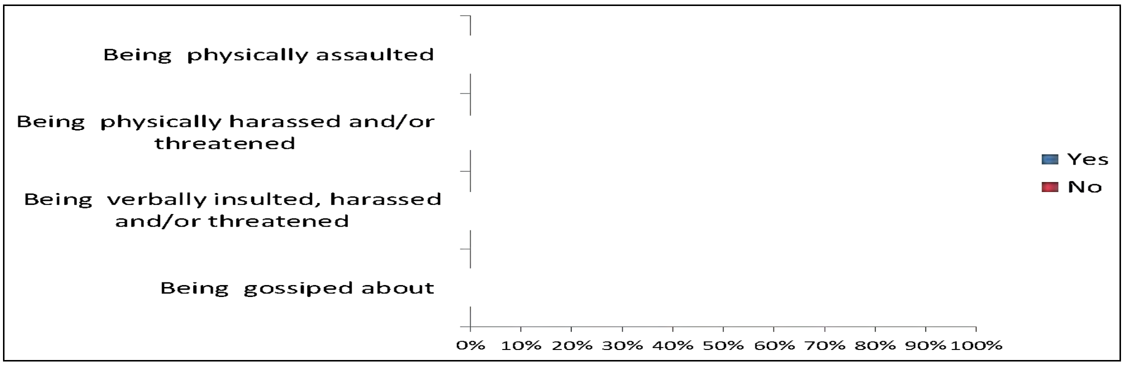


Table 14 shows respondents' fear of gossip, verbal and physical harassment, and physical assault disaggregated by sex, language and key population group. In all areas women reported higher levels of fear than men: being gossiped about (50% (n=55) compared to 36%

(n=67)), verbal insults (38% (n=42) compared to 24% (n=45)), threats of physical violence (24% (n=26) compared to 19% (n=35)), and physical assault (20% (n=22) compared to 15% (n=29)). Respondents who were Estonian speakers reported more fear of being gossiped about than Russian speakers (59% (n=17) to 39% (n=105)).

Significantly higher percentages of respondents, who identified as gay or lesbian, compared to the sample average, reported fears of being verbally harassed (67% to 29%), physically harassed (60% to 21%), and physically assaulted (53% to 17%). Those who identified as sex workers also reported high levels, than the sample average, of fear of verbal harassment (50% to 29%), physical harassment (31% to 21%) and physical assault (38% to 17%).

Table 14: Fear of gossip, verbal and physical harassment, and physical assault disaggregated by sex, language and key population group

	Men	Women	Russian speaker	Estonian speaker	Gay or Lesbian	Sex worker	Injecting drug user	Prisoner	TOTAL
Being gossiped about	36% (n=67)	50% (n=55)	39% (n=105)	59% (n=17)	60% (n=9)	33% (n=5)	40% (n=93)	31% (n=47)	41% (n=122)
Being verbally insulted, harassed, and/or threatened	24% (n=45)	38% (n=42)	29% (n=78)	31% (n=9)	67% (n=10)	50% (n=8)	31% (n=71)	23% (n=34)	29% (n=87)
Being physically harassed and/or threatened	19% (n=35)	24% (n=26)	21% (n=56)	17% (n=5)	60% (n=9)	31% (n=5)	20% (n=45)	17% (n=25)	21% (n=61)
Being physically assaulted	15% (n=29)	20% (n=22)	17% (n=46)	17% (n=5)	53% (n=8)	38% (n=6)	16% (n=37)	15% (n=22)	17% (n=51)

Half of the respondents (50%, n=149) reported fear in the last 12 months that other people did not want to have sexual relations with them because of their HIV-positive status, though half did not. A higher percentage of men than women (58% compared to 37%) and very high percentage of gay and lesbian respondents (87%, n=13) expressed this fear (**Table 15**).

Table 15: Fear of sexual rejection

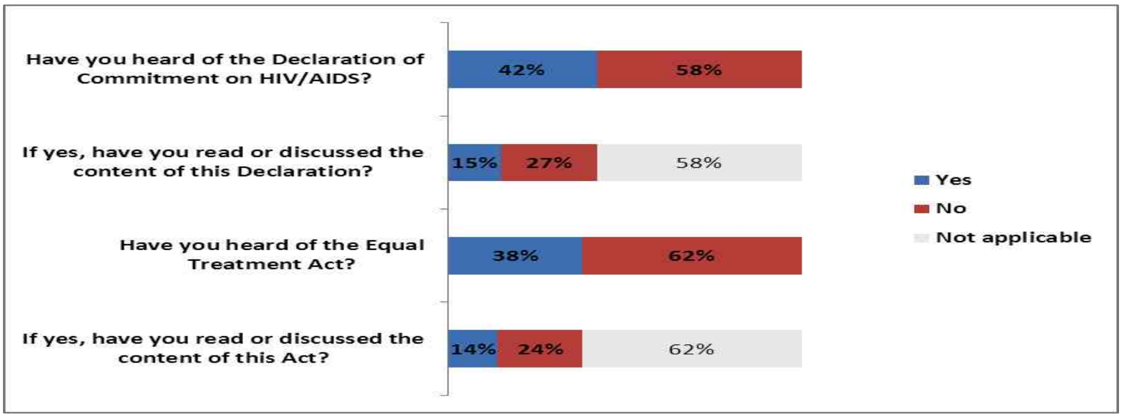
	Men	Women	Russian speaker	Estonian speaker	Gay or Lesbian	Sex worker	Injecting drug user	Prisoner	TOTAL
Fear that someone would not want to be sexually intimate with you	58% (n=108)	37% (n=41)	49% (n=132)	59% (n=17)	87% (n=13)	44% (n=7)	47% (n=109)	49% (n=74)	50% (n=149)

2.4 Rights, laws and policies

This sub-section focuses on awareness of the 2001 Declaration of Commitment on HIV[22] and knowledge of national laws (e.g. The Equal Treatment Act) and policies, as well as violations of rights experienced in various settings.

42% of respondents (n=124) had heard of The Declaration of Commitment on HIV/AIDS; of whom, 37% (n=45) had read or discussed the Declaration. The Estonian Equal Treatment Act[23] was known to 38% of respondents (n=113); of whom, 38% (n=43) had read or discussed it (**Chart 17**).

Chart 17: Familiarity with the Declaration of Commitment on HIV/AIDS and the Equal Treatment Act



In general, respondents from different groups answered these questions similarly. However:
Only 37% of Russian speakers: (n=99) had heard of the Equal Treatment Act compared to 56% of Estonian speakers (n=14).
Only 13% of sex workers (n=2) had heard of the Declaration of Commitment on HIV/AIDS compared to 43% (n=122) of non-sex workers.
Only 19% of sex workers (n=3) knew of the Equal Treatment Act, compared to 40% (n=110) of non-sex workers.

Discriminatory treatment by governmental, legal, and/or medical institutions

During the previous 12 months, 34% (n=103) of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions (**Chart 18**). The most frequent violation reported by 34% of respondents (n=101) was having been forced to submit to a medical procedure (including HIV testing). Smaller

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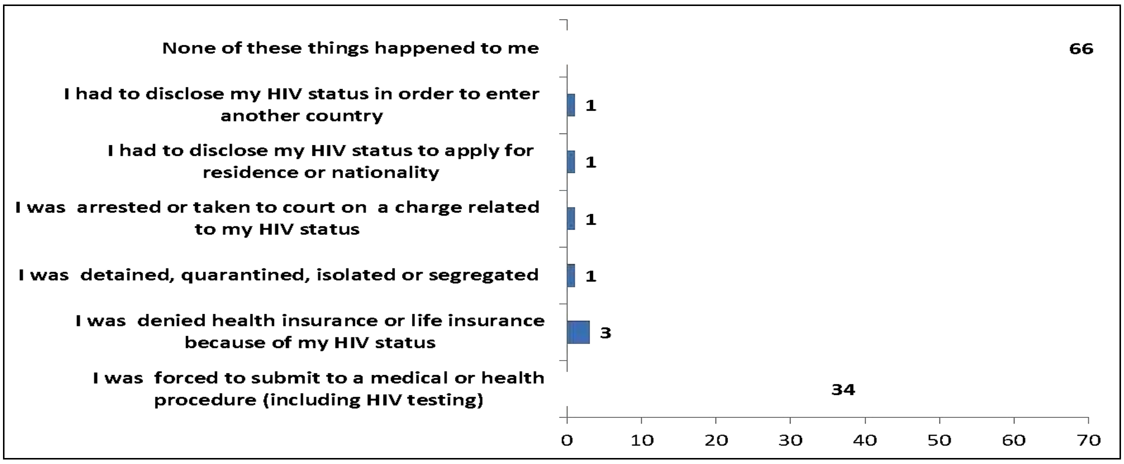
[22] http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf

[23] The full text of the Act can be found at http://www.erinevusrikastab.ee/en/materials/legislation

numbers of respondents indicated that they had been denied health or life insurance (3%, n=8); detained, quarantined, isolated, or segregated (1%, n=4); or arrested or taken to court on an HIV-related charge (1%, n=3). Two respondents (1%) indicated that they had to disclose their HIV status in order to enter another country and to apply for residence or nationality.

Chart 18: Percentage of respondents who reported discriminatory treatment by institutions



Any violation of the rights

7% of respondents (n=20) reported that their rights had been violated, and 15% (n = 30) were unsure of whether a violation of their rights had occurred. Of the 20 respondents who indicated a rights violation:

- 80% (n=16) were men and 20% (n=4) were women.
- 90% (n=18) were Russian speakers and 10% (n=2) were Estonian speakers.
- 10% (n=2) had lived with HIV for 1-4 years, 45% (n=9) for 5-9 years, and 45% (n=9) for 10-15 years.
- 70% (n=14) were current or former injecting drug users.
- 30% (n=6) were current or former prisoners and all also identified as people who use drugs.
- 15% were gay (n=1) or lesbian (n=2).

Three of 20 respondents (15%) had tried to get legal redress for abuse of rights as a person living with HIV within the previous 12 months. Two respondents indicated that the matter was not dealt with; while the other respondent indicated that the matter was still in process.

Of the 17 respondents who indicated that they experienced a rights violation and did not seek legal redress, the most common reason cited (50%, n=8) was the belief that the outcome would be unsuccessful (**Table 16**). Furthermore, only three respondents (15%) who had experienced an abuse of their rights reported trying to get a government employee to take action; of these, two had tried within the previous 12 months; though all indicated nothing had happened. Further, only the same three respondents (15%), who had experienced an abuse of their rights, had tried to get a local or national politician to take action, with the same outcome.

Table 16: Reasons for not seeking legal redress for rights violations

	Number	Percent
Insufficient financial resources	5	31%
Process of addressing the problem appeared to bureaucratic	3	19%
Felt intimidated or scared to take action	1	6%
Advised against taking action by someone else	1	6%
No/little confidence that the outcome would be successful	8	50%
None of the above	5	31%

Results equal more than 100% because multiple answers were possible

2.5 Effecting change

This section explores respondents' reactions to incidents of stigma and discrimination; awareness of potential sources of assistance when confronted with stigma and discrimination; and participation in policy reform on HIV-related stigma and discrimination.

Table 17 shows that 29% (n=86) of the respondents reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against him or her in the last 12 months.

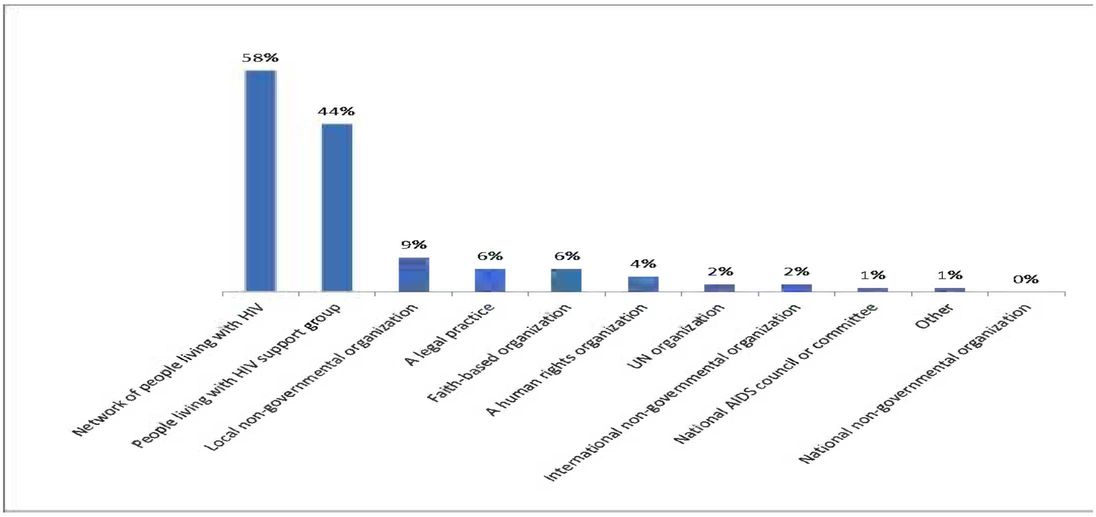
Women (28%) and men (29%), and Russian speakers (28%) and Estonian speakers (31%), were almost equally likely to indicate that they had responded to stigmatization or discrimination. Respondents who had the most severe food shortages (48%, n=27) and respondents who identified as gay or lesbian (53%, n=8) were significantly more likely to report confronting someone. In addition, respondents who belonged to a network of people living with HIV (36%, n= 21) and those with a technical college or university education (39%) were more likely to report that they had confronted someone who was stigmatizing them.

Table 17: Respondents who challenged stigma or discrimination directed at them

	Number answering "yes"	Percent answering "yes"
SEX		
Men	55	29%
Women	31	28%
LANGUAGE		
Russian language	77	28%
Estonian language	9	31%
KEY POPULATION		
Gay or lesbian	8	53% p=.030
Sex worker	7	44%
Injecting drug user	70	30%
Prisoner	43	29%
EDUCATION		
No formal education	4	24%
Primary school education	25	25%
Secondary school education	28	26%
Technical college/university education	28	39%
INCOME GROUP		
Lower income	30	29%
Average income	33	33%
Higher income	23	25%
FOOD INSECURITY GROUP		
No food shortages (previous month)	40	25%
Food shortages of 1-2 days (previous month)	3	27%
Food shortages of 3 or more days (previous month)	27	48% p=.004
MEMBER OF A PLHIV NETWORK		
Member of a people living with HIV network	21	36%
Not a member of a people living with HIV network	64	27%
TOTAL	**86**	**29%**

Overall, 68% (n=205) of the respondents knew of an organization or groups providing support to those experiencing stigma or discrimination. **Chart 19** shows respondents' knowledge of different types of organisations or groups providing support to those experiencing stigma or discrimination. Networks of people living with HIV were the most frequently cited entity to approach (58%); followed by 44% reporting knowledge of a support group for people living with HIV;. Each of the remaining types of organisation, including human rights organizations, local and national NGOs, FBOs and legal services, was mentioned by less than 10% of respondents.

Chart 19: The percentage of respondents identifying each kind of organization that offers help in cases of stigma and discrimination



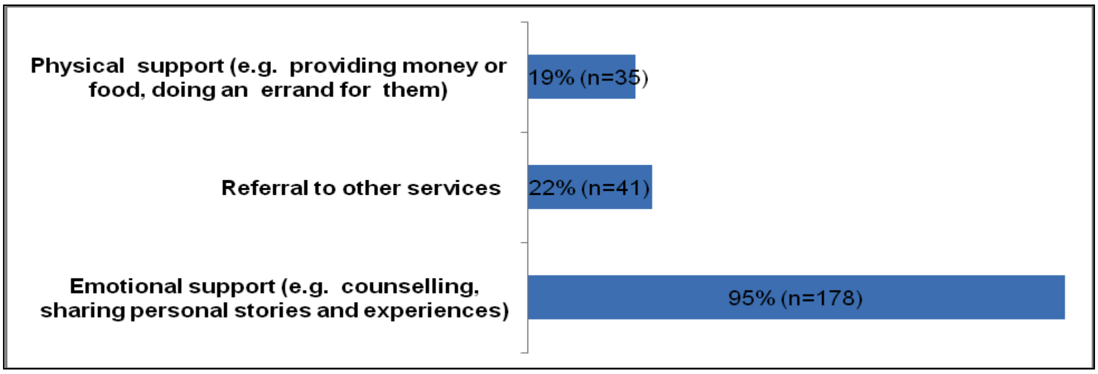
Getting help in a case of a problem and solutions

Fifteen respondents (5%) indicated that they had sought help from the types of organizations listed above.

Helping other HIV-positive people

Chart 20 outlines the types of support respondents reported providing to other people living with HIV in the previous 12 months. Emotional support (in the form of counselling, sharing personal stories and experiences) was the most common type of assistance rendered (95%, n=178), with 22% (n=41) indicating that they had provided a referral to other services, while 19% (n=35) provided physical support (such as running errands and providing food or money).

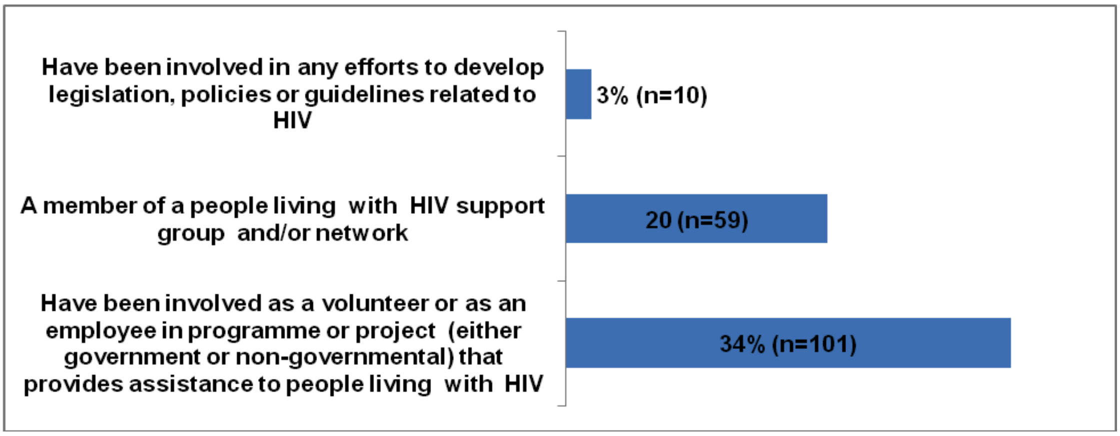
Chart 20: Supporting other HIV-positive people



Note that multiple responses were permissible. Therefore percentages do not add up to 100%.

Among the respondents, 34% (n=101) reported being a member of a support group and/or network of people living with HIV. Respondents were also asked to indicate whether in the previous 12 months, they had been involved (as a volunteer or employee) in a programme or project providing assistance to people living with HIV: 20% (n=59) reported being involved (**Chart 21**).

Chart 21: Member of a people living with HIV network/support group, and involvement as employee/volunteer in HIV programmatic work, and involvement in policy making



Most respondents (97%) indicated that in the previous 12 months, they had not been involved in efforts to develop legislation, policies or guidelines relating to HIV with only 3% (n=10) reporting such involvement (**Table 18**). Subgroup differences, based on language group, level of food insecurity, level of education, and whether the respondent was a member of a PLHIV support group or network were evident in the responses, as shown in **Table 18**.

The following were more likely to report that they had been a volunteer or employee in a programme to provide assistance to people living with HIV:

- Russian speakers: 37% compared to 4% of Estonian speakers.
- Respondents with the highest levels of education (53% (n=38) compared to 29% (n=29) of those with primary level education).
- Respondents who faced serious food shortages (46% (n=26) compared to 24% (n=39) of those with no food shortages).
- Respondents who were members of a PLHIV support group or network (64% (n=38) compared to 26% (n=63) of those who were not members).

In addition, all of the respondents who reported that they had been involved in efforts to develop legislation, policies, or guidelines related to HIV were members of a PLHIV support group or network (n=15).

Table 18: Involvement in PLHIV support group or network, programme activities, or legislation and policy development in last 12 months

	Member of the Estonian Network of PLHIV	A volunteer or employee in a programme or project that provides assistance to people living with HIV	Involved in efforts to develop legislation, policies, or guidelines related to HIV
SEX			
Men	18% (n=34)	35% (n=66)	3% (n=6)
Women	23% (n=25)	32% (n=35)	4% (n=4)
LANGUAGE			
Russian language	20% (n=55)	37% (n=100)	4% (n=10)
Estonian language	14% (n=4)	4% (n=1)	0% (n=0)
KEY POPULATION			
Gay or lesbian	27% (n=4)	40% (n=6)	0% (n=0)
Sex worker	6% (n=1)	19% (n=3)	0% (n=0)
Injecting drug user	20% (n=47)	35% (n=80)	4% (n=9)
Prisoner	15% (n=23)	37% (n=56)	2% (n=3)
EDUCATION			
No formal education	18% (n=3)	35% (n=6)	0% (n=0)
Primary school education	13% (n=13)	29% (n=29)	2% (n=2)
Secondary school education	21% (n=23)	26% (n=28)	5% (n=5)
Technical college/university education	28% (n=20)	53% (n=38)	4% (n=3)
INCOME GROUP			
Lower income	19% (n=20)	34% (n=35)	3% (n=3)
Average income	19% (n=19)	37% (n=37)	4% (n=4)
Higher income	22% (n=20)	31% (n=29)	3% (n=3)
FOOD INSECURITY GROUP			
No food shortages (previous month)	23% (n=37)	24% (n=39)	3% (n=5)
Food shortages of 1-2 days (previous month)	9% (n=1)	36% (n=4)	0% (n=0)
Food shortages of 3 or more days (previous month)	21% (n=12)	46% (n=26)	2% (n=1)
MEMBER OF A PLHIV NETWORK			
Member of a people living with HIV network		64% (n=38)	15% (n=9)
Not a member of a people living with HIV network		26% (n=63)	0% (n=1)
TOTAL	**20% (n=59)**	**34% (n=101)**	**3% (n=10)**

Chart 22 focuses on respondents' feelings of being able to influence policies, laws and programmes. Nearly 40% of respondents felt able to influence local projects to benefit people living with HIV (39.8%, n=340) and legal/rights matters affecting people living with HIV (37.6%, n= 321). However, less than one in five respondents felt that they had any influence at the national programmatic level (12.4%, n=106) or on local or national policies (18.5%, n=158 and

16.7%, n=143, respectively). Furthermore, over 80% (81%, n=242) of respondents felt unable to influence any of the areas mentioned. The most common areas in which respondents felt that had the power to influence decisions were in local projects and national programmes/projects intended to benefit people living with HIV (12%, n=35; 6%, n=17, respectively).

Chart 22: Feelings of being able to influence policies, laws and programmes

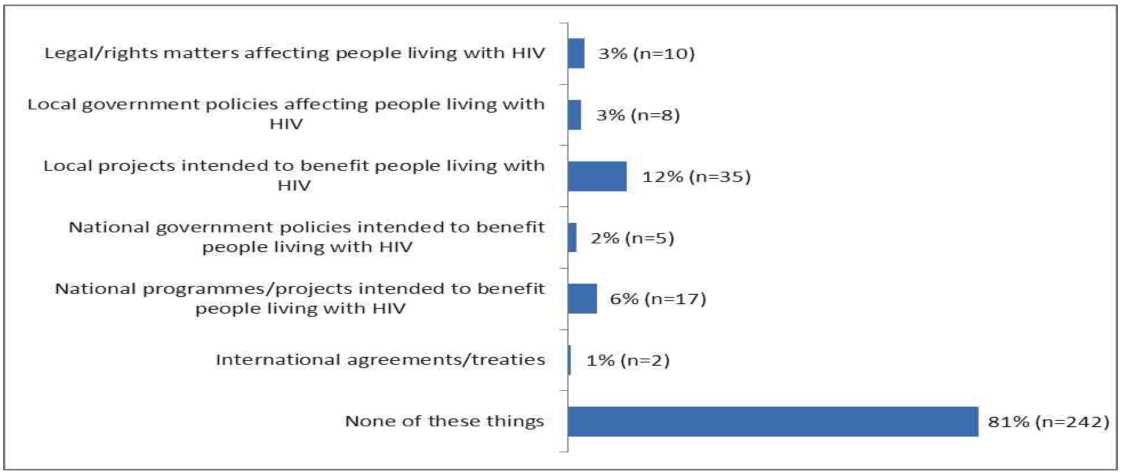
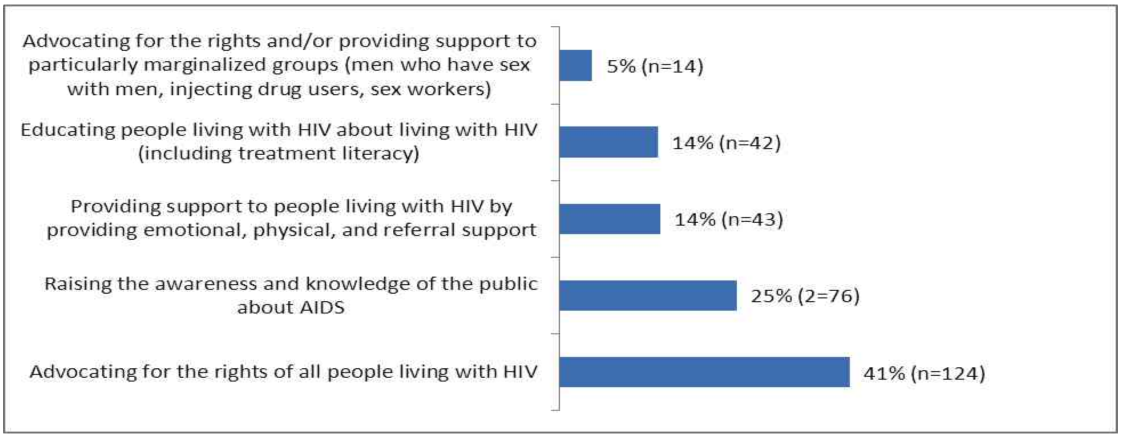


Chart 23 outlines respondents' recommendations, disaggregated by age, regarding the most important things organisations should do to address stigma and discrimination.

More than 40% (41%, n=124) of respondents cited advocating for the rights of all people living with HIV; while one quarter cited raising public awareness and knowledge of AIDS and 14% cited both educating people living with HIV about living with HIV and providing emotional, physical and referral support as the most important strategies organisations should adopt to address stigma and discrimination. Only 5% (n=14) mentioned work in support of particularly marginalised groups.

Chart 23: Recommendations for organization working against stigma and discrimination, n = 299



Section 3: Experience of testing, disclosure, treatment and having children

This Section comprises four sub-sections: testing and diagnosis; disclosure and confidentiality; treatment; and experience of having children.

3.1 Testing and diagnosis

Chart 24 shows that among respondents, 43% (n=130) reported taking a HIV test just to know their status. Note, however, that 7% (n=21) were referred for HIV testing when already symptomatic. In addition, 32% of respondents (n=95) selected the option 'Other'. These respondents were asked to describe the reason for their HIV test in their own words. The responses were analysed and coded. Two recurrent themes emerged:

- respondents were tested while in prison (21%, n=64); or
- respondents were tested during the process of other medical procedures (7%, n=21).

Of these, the most frequent event was being tested while in prison. Examples of this response included: HIV test was taken in prison, it is mandatory in prison. Or, frequently, the simple response: Prison. In the sample, there were a total of 151 respondents who identified as prisoners or former prisoners. The response to this question indicates that 42% (64 out of 151) of the current or former prisoners learned of their HIV-positive status while in prison.

An additional 7% (n=21) of the sample indicated that they were tested for HIV during the process of another medical procedure. These responses included:

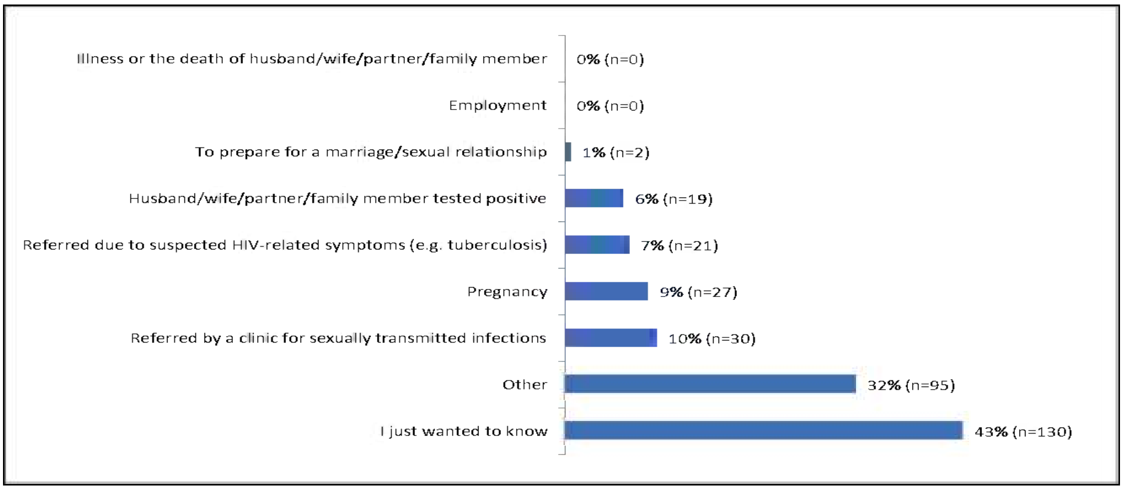
- *Preparing for artificial insemination.*
- *I was in an infectious disease hospital because of my liver, a HIV test was taken.*
- *I was a donor.*
- *During childbirth.*
- *Because of pneumonia doctors asked me to undergo the test, I did it and discovered that I have HIV infection.*
- *I suspected encephalitis, the tests were taken and HIV-positive status was determined.*
- *I had an overdosed and while I was unconscious a HIV test was taken.*

It should be noted that while some of these examples include coerced HIV testing, others are further examples of HIV testing when some respondents were symptomatic, increasing the overall percentage of those undergoing HIV testing when already symptomatic.

The remaining 10 miscellaneous responses (3%) included:

- *When I entered the methadone program I underwent a HIV test.*
- *I used drugs previously and that is why I underwent the test (agreed to).*
- *My family members forced me to do the test (I ran away from home).*

Chart 24: Reasons for undergoing HIV testing



Note: It was permissible to select multiple responses.

Decision to undergo HIV test

Respondents were asked about their decision to be tested for HIV and whether their HIV test was undertaken voluntarily, under pressure or coercion, or without their knowledge (**Table 19**). Overall, slightly less than two-thirds of the respondents (63%, n=189) indicated that their HIV test was completely voluntarily. 31 respondents (10%) reported that they were forced to take a HIV test, while 26 respondents (9%) indicated that they were tested under pressure from others. The remaining 18% (n=53) reported that they were tested without their knowledge.

There were no real differences in responses by gender. However, respondents who spoke Estonian were much more likely than those who spoke Russian to indicate that they tested voluntarily (93%, (n=27) compared to 60%, (n=162)).

With regards to key populations, the experience of being forced or pressured to take a HIV test was particularly notable among prisoners and sex workers. Only half of the respondents who were, or had been, prisoners (50%, n=76) or sex workers (50%, n=8) reported that they underwent testing voluntarily. Prisoners were much more likely than non-prisoners to report that they were coerced to have a HIV test (18%, n=27 compared to 3%). Both prisoners and sex workers were more likely to report testing under pressure from others (with 13% (n=19) of prisoners compared to 5% of non-prisoners and 25% (n=4) of sex workers compared to 8% of non-sex workers). In addition, respondents with the highest reported levels of food insecurity were more likely to have been coerced to test, 18% (n=10), compared to 10% (n=16) with no food insecurity or tested without their knowledge, 27% (n=15), compared to 13% (n=21) with no food insecurity.

More respondents who were recently diagnosed reported that they had tested voluntarily. Of those who had lived with HIV for four years or less (0-1 year: 75% (n=15) to 1-4 years 78% (n=65)) reported testing voluntarily; while of the respondents who had been living with HIV for between 5 and 14 years: 5-9 years: 58% (n=74) and 10-14 years: 49% (n=34) reported testing voluntarily. These results suggest, tentatively that, in recent years, fewer people may be being coerced or tested without their knowledge, but requires further study.

Table 19: HIV testing: undertaken voluntarily, pressure, coercion, or without respondent's knowledge disaggregated by gender, language, key population, age, length of time living with HIV, education, income and food security

	Yes, I took the decision myself to be tested (i.e. it was voluntary)	I took the decision to be tested, but it was under pressure from others	I was made to take an HIV test (coercion)	I was tested without my knowledge – I only found out after the test had been done
GENDER				
Men	61% (n=115)	10% (n=18)	12% (n=22)	18% (n=34)
Women	68% (n=74)	8% (n=9)	8% (n=9)	17% (n=19)
LANGUAGE				
Russian language	60% (n=162)	10% (n=27)	11% (n=30)	19% (n=52)
Estonian language	93% (n=27)	0% (n=0)	3% (n=1)	3% (n=1)
KEY POPULATION				
Gay or lesbian	73% (n=11)	13% (n=2)	7% (n=1)	7% (n=1)
Sex worker	50% (n=8)	25% (n=4)	13% (n=2)	13% (n=2)
Injecting drug user	61% (n=141)	10% (n=23)	11% (n=25)	19% (n=43)
Prisoner	50% (n=76)	13% (n=19)	18% (n=27)	19% (n=29)
LENGTH OF TIME LIVING WITH HIV				
0-1 year	75% (n=15)	15% (n=3)	5% (n=1)	5% (n=1)
1-4 years	78% (n=65)	4% (n=3)	10% (n=8)	8% (n=7)
5-9 years	58% (n=74)	9% (n=11)	8% (n=10)	25% (n=32)
10-14 years	49% (n=34)	15% (n=10)	17% (n=12)	19% (n=13)
15+ years	100% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)

Counselling during HIV-testing

QUESTION 3: „Did you receive counselling when you were tested for HIV?"

Table 20 outlines respondents reported access to counselling during HIV testing. Just under a third (32%, (n=96) of respondents received both pre- and post-test counselling; however, just over a third (34%, (n=101) received no counselling at all, while nearly a third (32%, n=97)) received only post-test counselling, and 2% (n=6) received only pre-test counselling.

The largest difference in pre- and post-test counselling was seen between Estonian and Russian speakers. More than 3 out of 4 Estonian speakers indicated that they received both pre- and post-test counselling (76%, n=22); while just over 1 out of 4 Russian speakers indicated that they received both periods of counselling (27%, n=74). Similarly, 36% of Russian speakers (n=98) reported no HIV-test counselling at all compared with 10% of Estonian speakers (n=3).

Respondents who were living with HIV for four or fewer years were much more likely to indicate that they received both pre- and post-testing counselling. Respondents who had been living with HIV for more than four years were more likely to report no HIV-test counselling at all when they were tested.

Table 20: Access to counselling during HIV testing

	I received both pre- and post-HIV test counselling	**I only received pre-test HIV counselling**	**I only received post-test HIV counselling**	**I did not receive any counselling when I had an HIV test**
GENDER				
Men	34% (n=65)	2% (n=3)	31% (n=59)	33% (n=62)
Women	28% (n=31)	3% (n=3)	34% (n=38)	35% (n=39)
LANGUAGE				
Russian language	27% (n=74)	2% (n=6)	34% (n=93)	36% (n=98)
Estonian language	76% (n=22)	0% (n=0)	14% (n=4)	10% (n=3)
LENGTH OF TIME LIVING WITH HIV				
0-1 year	70% (n=14)	0% (n=0)	15% (n=3)	15% (n=3)
1-4 years	39% (n=32)	4% (n=3)	29% (n=24)	29% (n=24)
5-9 years	26% (n=33)	1% (n=1)	39% (n=50)	34% (n=43)
10-14 years	23% (n=16)	3% (n=2)	29% (n=20)	45% (n=31)
15+ years	100% (n=1)	0% (n=0)	0% (n=0)	0% (n=0)
EDUCATION				
No formal education	53% (n=9)	6% (n=1)	29% (n=5)	12% (n=2)
Primary school education	26% (n=26)	3% (n=3)	32% (n=32)	39% (n=39)
Secondary school education	36% (n=40)	1% (n=1)	33% (n=36)	30% (n=33)
Technical college/university education	29% (n=21)	1% (n=1)	33% (n=24)	36% (n=26)
TOTAL	**32% (n=96)**	**2% (n=6)**	**32% (n=97)**	**34% (n=101)**

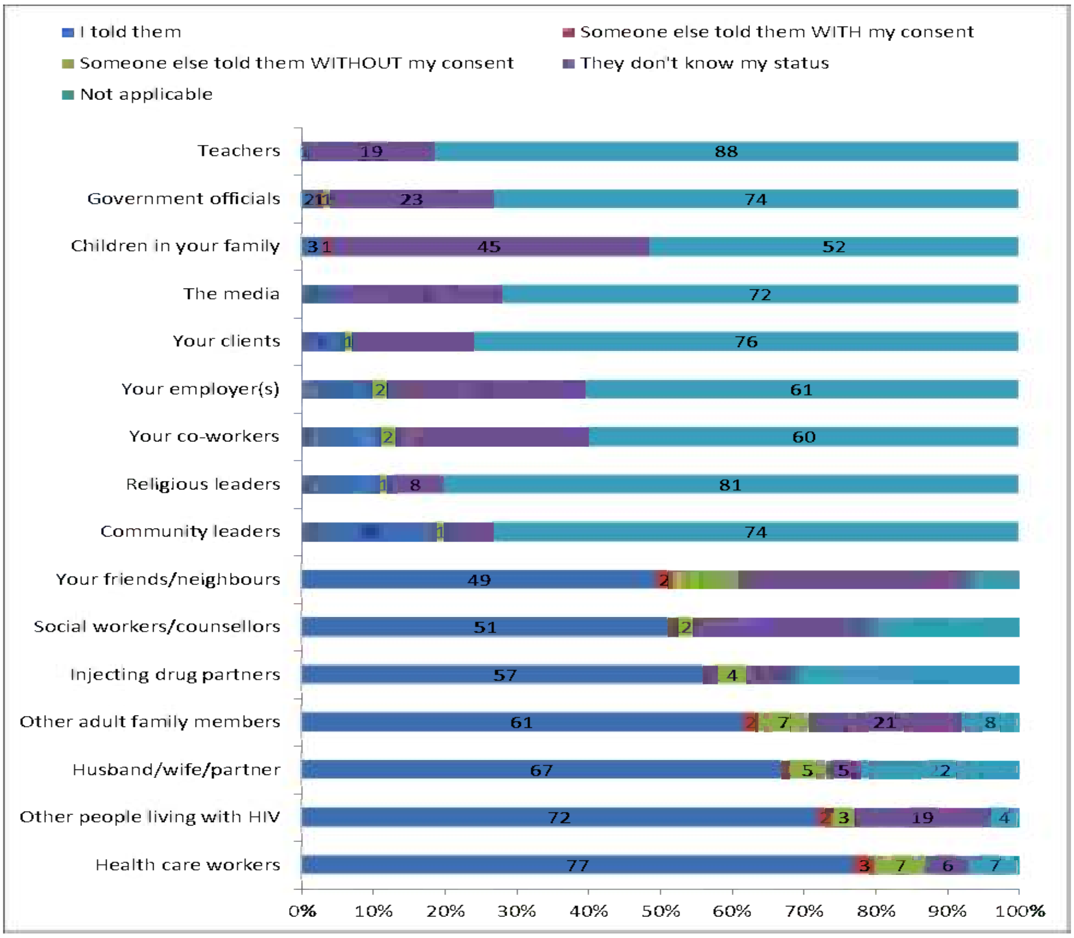
3.2 Disclosure and confidentiality

In **Chart 25,** the highest percentages of respondents had disclosed their status to health care workers (77%), other HIV-positive people (72%), spouses or partners (67%), and other adult family members (61%), injecting drug partners (57%), and social workers and other counsellors (51%).

Many respondents had not disclosed their HIV status to their children (45%), or to their employers (28%) or co-workers (27%). A quarter (25%, n=74) had not disclosed their status to social workers and other counsellors, and 6% had not disclosed to health care workers. In 21% (n=63) of the cases, respondents had not told any other adult family members (not including the spouse or partner) about their status.

The types of people who were most likely to have learned of a respondent's HIV status without the respondents' consent were friends or neighbours (9%, n=27), health care workers (7%, n=21) and adult family members (7%, n=22).

Chart 25: Disclosure of HIV-positive status to others

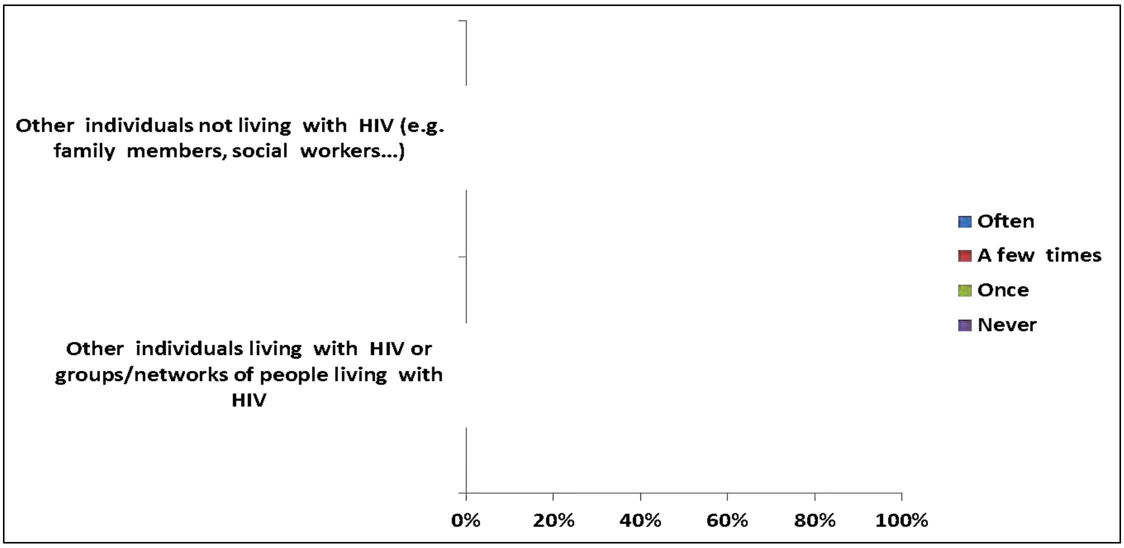


n = 288 to 296, percentage reported is the percentage of respondents who answered each question

Chart 26, shows that overall, most respondents reported that they had not felt pressured to disclose their HIV status by others:

- 77% of respondents indicated that they had never felt pressure by other individuals who were not living with HIV, though 23% had.
- 82% of respondents indicated that they had never felt pressure by other individuals who were living with HIV, though 18% had.

Chart 26: Pressure to disclose HIV-positive status



Overall 22% of respondents with 23% of males (n=42) and 21% of females (n=23) reported that a health care professional (for example, a doctor, nurse, counsellor, laboratory technician) had told other people about their HIV status without their consent. 42% of respondents reported no such disclosure; while 36% were unsure. Russian speakers were more significantly more likely to report violations of confidentiality by health care workers than Estonian speakers (24% (n=64) compared to 4% (n=1). Furthermore, respondents with a history of drug use were twice as likely to report violations of confidentiality by health care workers as people without a history of drug use (25% (n=57) compared to 12% (n=8).

Just under a quarter of respondents (24%, n=70) think that their medical records are completely confidential; though nearly half (46%, n=134) indicated that they do not know if their records are kept confidential; while it was clear to 30% (n=89) of respondents that their medical records were not being kept confidential.

Reactions of other people to respondents' HIV-positive status

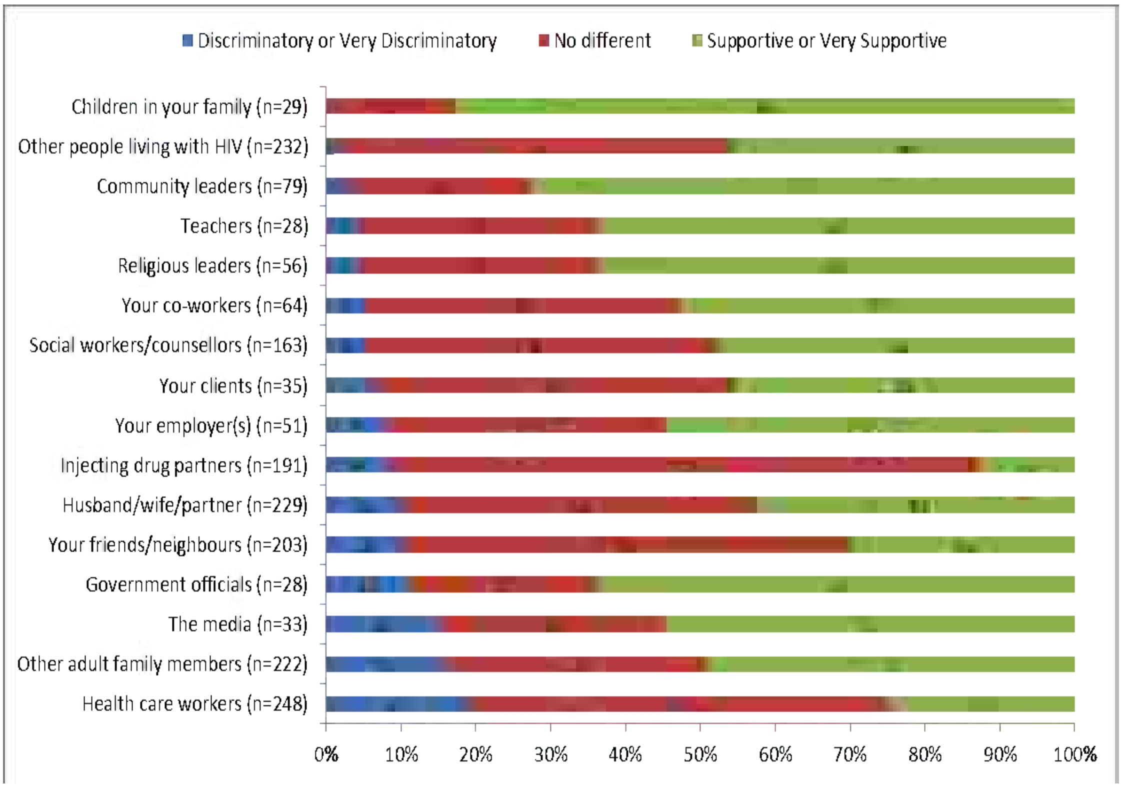
Respondents were asked about the reactions of different people when they first knew about their HIV status. **Chart 27** shows perceived reactions, with categories ranging from very discriminatory to very supportive, with respondents' answers only included in instances in which the question was applicable. Note that in the following analysis that the responses for discriminatory and very discriminatory and for supportive and very supportive were combined.

It is important to note that some of the categories represent people, or groups of people, with whom respondents can often use their discretion about whether or not to disclose (for example, children or employers). With other categories, the reasons to disclose may be more pressing (for example, health care workers or partners and spouses). The more discretion that respondents feel that they can exercise in deciding who should know their HIV-status, the more support one would expect to find in **Figure 65**. This is because respondents have more ability to decide to keep their HIV-status private from people who are expected to mistreat them.

Respondents reported varying reactions from spouses and partners, with 10% saying that their spouses or partners reactions were discriminatory or very discriminatory and 43% saying that their spouses or partners were supportive or very supportive. In 16% of cases, respondents reported that they faced discriminatory reactions by family members and in 50% of the cases the respondents were supported by the family members; while 35% of the adult family members did not change their attitude.

Health care workers reported as having the highest levels of discriminatory reactions (19%). However, the reactions of health care workers also varied: in 25% of cases, the health care workers' attitude was supportive or very supportive, and more than half of health care workers (56%) did not change their attitude. High percentages of respondents reported supportive responses by children in their family (83%), community leaders (73%), teachers, religious leaders, and government officials (64% each).

Chart 27: Perceived reactions to disclosure



While approximately half of men and women described disclosing their HIV status as an empowering experience (50% (n=95) and 52% (n=58), respectively); more men than women said that disclosure had not been a positive experience (41% (n=78) compared to 24% (n=27)). More respondents who belonged to a PLHIV network, 59% (n=35), reported that disclosure had been a positive experience than respondents who did not belong to a PLHIV network 49% (n=118).

The data suggest associations between low-income level and severe food insecurity, and positive experience of disclosure. For example, 38% (n=21) of those with severe food insecurity indicated that disclosure was a positive experience compared with 63% (n=102) of those with no food insecurity; and 43% (n=45) of those with the low income reported that disclosure was a positive experience, compared with 59% (n=55) of those with the high income. In addition, those with the lowest income and those with the highest food insecurity had the highest percentages of people who had not disclosed their HIV status (28% and 20%, respectively).

Table 21: Disclosure of HIV status and feelings of empowerment, disaggregated by gender, language, key population, age, length of time living with HIV, education, income, food security and member of a PLHIV network

	Yes	No	Not Applicable
SEX			
Men	50% (n=95)	41% (n=78)	9% (n=16)
Women	52% (n=58)	24% (n=27)	23% (n=26)
LANGUAGE			
Russian language	49% (n=133)	36% (n=98)	15% (n=40)
Estonian language	69% (n=20)	24% (n=7)	7% (n=2)
KEY POPULATION			
Gay or lesbian	40% (n=6)	40% (n=6)	20% (n=3)
Sex worker	75% (n=12)	25% (n=4)	0% (n=0)
Injecting drug user	50% (n=117)	35% (n=82)	14% (n=33)
Prisoner	54% (n=82)	36% (n=54)	14% (n=42)
AGE			
15-19 years	100% (n=2)	0% (n=0)	0% (n=0)
20-24 years	50% (n=20)	33% (n=13)	18% (n=7)
25-29 years	45% (n=53)	36% (n=43)	19% (n=23)
30-39 years	53% (n=64)	37% (n=45)	10% (n=12)
40-49 years	81% (n=13)	19% (n=3)	0% (n=0)
50+ years	50% (n=1)	50% (n=1)	0% (n=0)
LENGTH OF TIME LIVING WITH HIV			
0-1 year	45% (n=9)	35% (n=7)	20% (n=4)
1-4 years	39% (n=32)	40% (n=33)	22% (n=18)
5-9 years	62% (n=79)	28% (n=36)	9% (n=12)
10-14 years	48% (n=33)	41% (n=28)	12% (n=8)
15+ years	0% (n=0)	100% (n=1)	0% (n=0)
EDUCATION			
No formal education	35% (n=6)	24% (n=4)	41% (n=7)
Primary school education	50% (n=50)	36% (n=36)	14% (n=14)
Secondary school education	57% (n=63)	31% (n=34)	12% (n=13)
Technical college/university education	46% (n=33)	43% (n=31)	11% (n=8)
INCOME GROUP			
Lower income	43% (n=45)	29% (n=30)	28% (n=29)
Average income	51% (n=51)	41% (n=41)	8% (n=8)
Higher income	59% (n=55)	37% (n=34)	4% (n=4)
FOOD INSECURITY GROUP			
No food shortages (previous month)	63% (n=102)	34% (n=55)	4% (n=6)
Food shortages of 1-2 days (previous month)	64% (n=7)	18% (n=2)	18% (n=2)
Food shortages of 3 or more days (previous month)	38% (n=21)	43% (n=24)	20% (n=11)
MEMBER OF A PLHIV NETWORK			
Member of a people living with HIV network	59% (n=35)	27% (n=16)	14% (n=8)
Not a member of a people living with HIV network	49% (n=118)	37% (n=88)	14% (n=34)
TOTAL	**51% (n=153)**	**35% (N=105)**	**14% (n=42)**

3.3 Treatment

Respondents were asked to provide information on how they perceived their current health, their access to treatment for opportunistic infections and their experiences of sexual and reproductive health information in health care facilities. Only (7%) described their health as 'excellent' or ‘very good’. Two thirds of respondents (66%) indicated that their current health was ‘fair’ or ‘poor’, while (27%) described their health as ‘good’. In addition, the longer people have lived with HIV the more frequently respondents described their health as ‘fair’ or ‘poor’. Respondents with high levels of food insecurity reported ‘fair’ or ‘poor’ health more often than those with no food insecurity (89% compared to 53%) (**Table 22**).

Table 22: Descriptions of current health

	Excellent	Very Good	Good	Fair	Poor
SEX					
Men	3% (n=6)	5% (n=10)	28% (n=53)	43% (n=82)	20% (n=38)
Women	0% (n=0)	5% (n=6)	24% (n=27)	52% (n=58)	18% (n=20)
LANGUAGE					
Russian language	2% (n=6)	5% (n=13)	24% (n=64)	49% (n=132)	21% (n=56)
Estonian language	0% (n=0)	10% (n=3)	55% (n=16)	28% (n=8)	7% (n=2)
KEY POPULATION					
Gay or lesbian	0% (n=0)	7% (n=1)	47% (n=7)	33% (n=5)	13% (n=2)
Sex worker	0% (n=0)	13% (n=2)	44% (n=7)	44% (n=7)	0% (n=0)
Injecting drug user	2% (n=5)	4% (n=10)	23% (n=54)	49% (n=114)	21% (n=49)
Prisoner	4% (n=6)	4% (n=6)	25% (n=38)	46% (n=70)	21% (n=31)
AGE					
15-19 years	0% (n=0)	0% (n=0)	50% (n=1)	50% (n=1)	0% (n=0)
20-24 years	0% (n=0)	13% (n=5)	35% (n=14)	43% (n=17)	10% (n=4)
25-29 years	2% (n=2)	6% (n=7)	24% (n=28)	47% (n=56)	22% (n=26)
30-39 years	3% (n=4)	3% (n=4)	27% (n=33)	46% (n=56)	20% (n=24)
40-49 years	0% (n=0)	0% (n=0)	25% (n=4)	56% (n=9)	19% (n=3)
50+ years	0% (n=0)	0% (n=0)	0% (n=0)	50% (n=1)	50% (n=1)
LENGTH OF TIME LIVING WITH HIV					
0-1 year	0% (n=0)	25% (n=5)	50% (n=10)	25% (n=5)	0% (n=0)
1-4 years	1% (n=1)	5% (n=4)	39% (n=32)	43% (n=36)	12% (n=10)
5-9 years	1% (n=1)	5% (n=6)	20% (n=25)	51% (n=65)	24% (n=30)
10-14 years	6% (n=4)	1% (n=1)	19% (n=13)	48% (n=33)	26% (n=18)
15+ years	0% (n=0)	0% (n=0)	0% (n=0)	100% (n=1)	0% (n=0)
MEMBER OF A PLHIV NETWORK					
Member of a people living with HIV network	2% (n=1)	9% (n=5)	25% (n=15)	51% (n=30)	14% (n=8)
Not a member of a people living with HIV network	2% (n=5)	5% (n=11)	27% (n=64)	46% (n=110)	21% (n=50)
TOTAL	**2% (n=6)**	**5% (n=16)**	**27% (n=80)**	**47% (n=140)**	**19% (n=57)**

Chart 28 shows that 59% (n=177) of respondents were taking ART at the time of the survey with 94% (n=283) indicating that they could access ART if needed (i.e. it is free of charge or the person can afford it). Some 12% (n=35) of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections, and 64% (n=190) reported having access to these medications even if they were not currently taking it; however, 14% (n=43) indicated that they do not have access and 22% (n=66) did not know if they could access this medication.

66% (n=198) indicated that they discussed HIV treatment options with a health care professional during last 12 months. 40% (n=121) reported that they have discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months

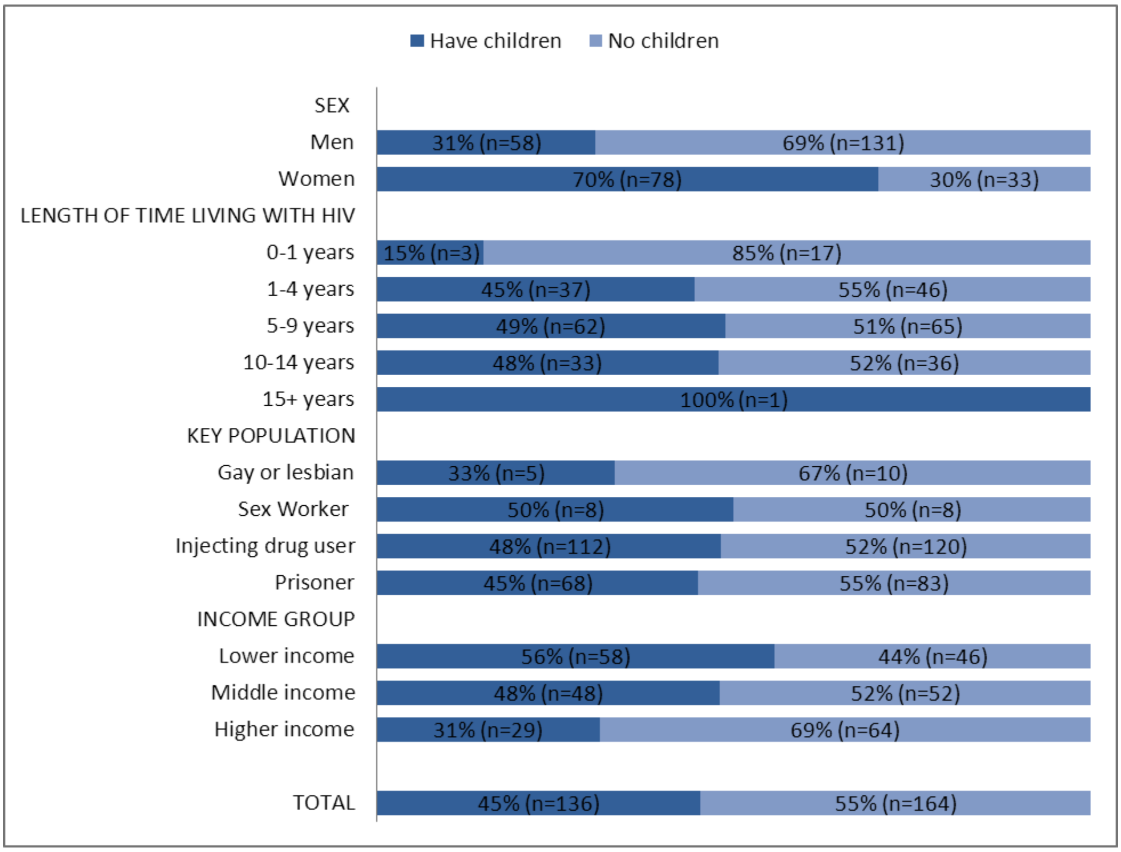
Chart 28: Treatment and treatment options during last 12 months

3.4 Having children

This sub-section focuses on respondents' experiences regarding reproductive options and sexual and reproductive health services. Female respondents were asked additional questions relating to pregnancy and infant feeding practices.

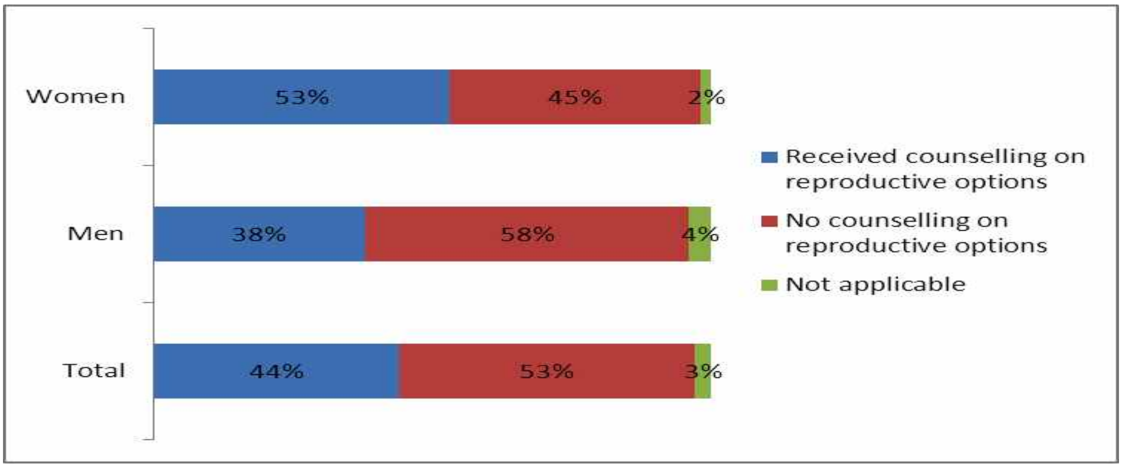
Of the sample, 136 respondents (45%) indicated that they had children (**Chart 29**). Women and those in the lowest income group were substantially more likely to have children (70% (n=78) and 56% (n=58), respectively). Two respondents, both women, indicated that one or more of their children were HIV-positive (3%).

Chart 29: Respondents with children



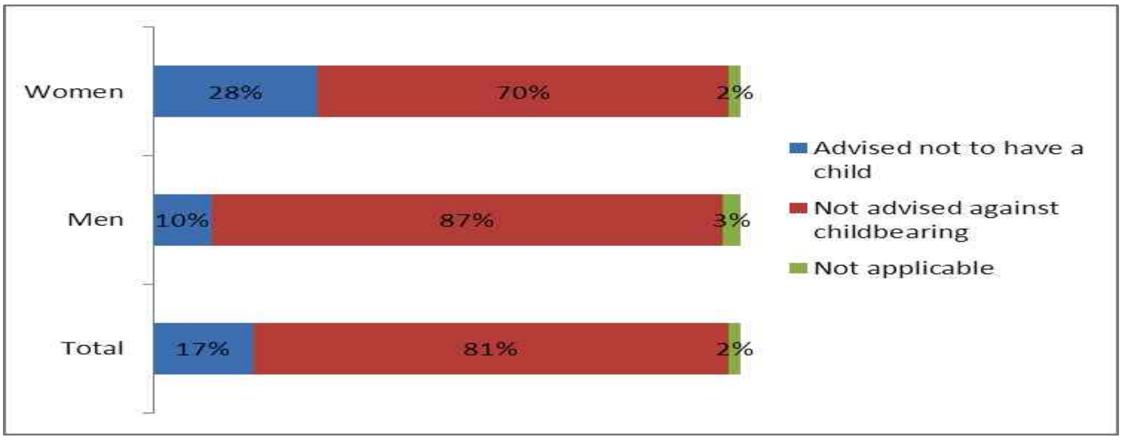
More than half of respondents (53%, n= 156) indicated that they had never received counselling on their reproductive options since their HIV diagnosis with men significantly less likely than women to have received such counselling (38% compared to 53%) (**Chart 30**).

Chart 30: Counselling on reproductive options, n=295 (186 men, 109 women)



Of the respondents, 17% (n=50) reported that they have been advised by a health care worker not to have a child since their diagnosis with women significantly more likely to report this, 28% (n=31), than men, 10% (n=19) (**Chart 31**).

Chart 31: Advised by health care professional not to have a child since diagnosis

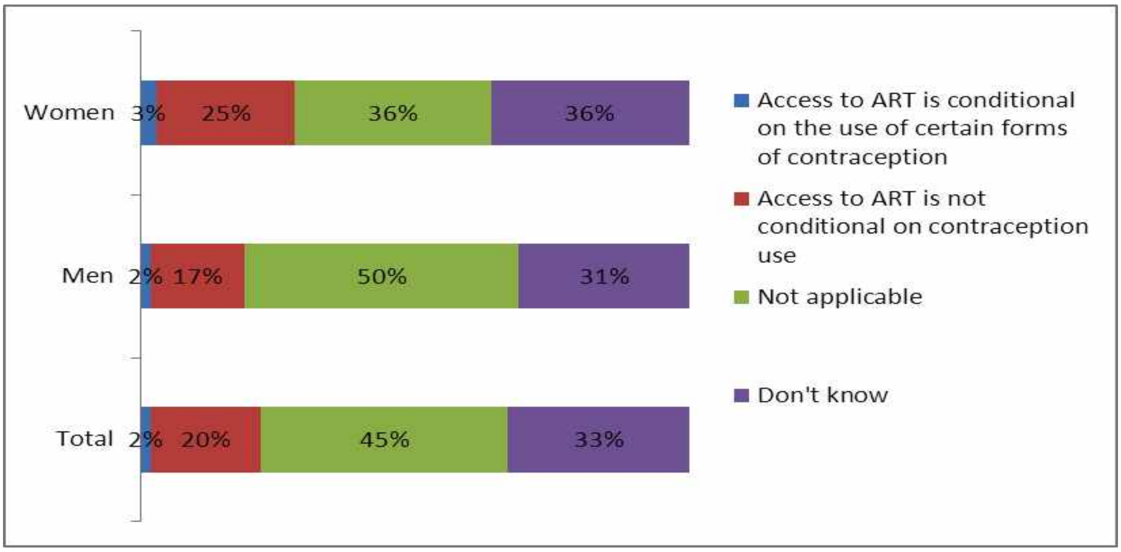


Ten respondents (3%), of whom 8 were women and 2 were men, reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis (**Chart 32**). All ten respondents identified as being current or former people who use drugs (equal to 4% of those who identified as injecting drug users). There were no other meaningful differences based on key population membership.

Chart 32: Coerced sterilization by health care workers

Seven respondents (2%), including 3 women (3%) and 4 men (2%), reported that their ability to obtain ART was conditional on using certain forms of contraception (**Chart 33**).

Chart 33: Access to antiretroviral treatment is conditional based on contraception use

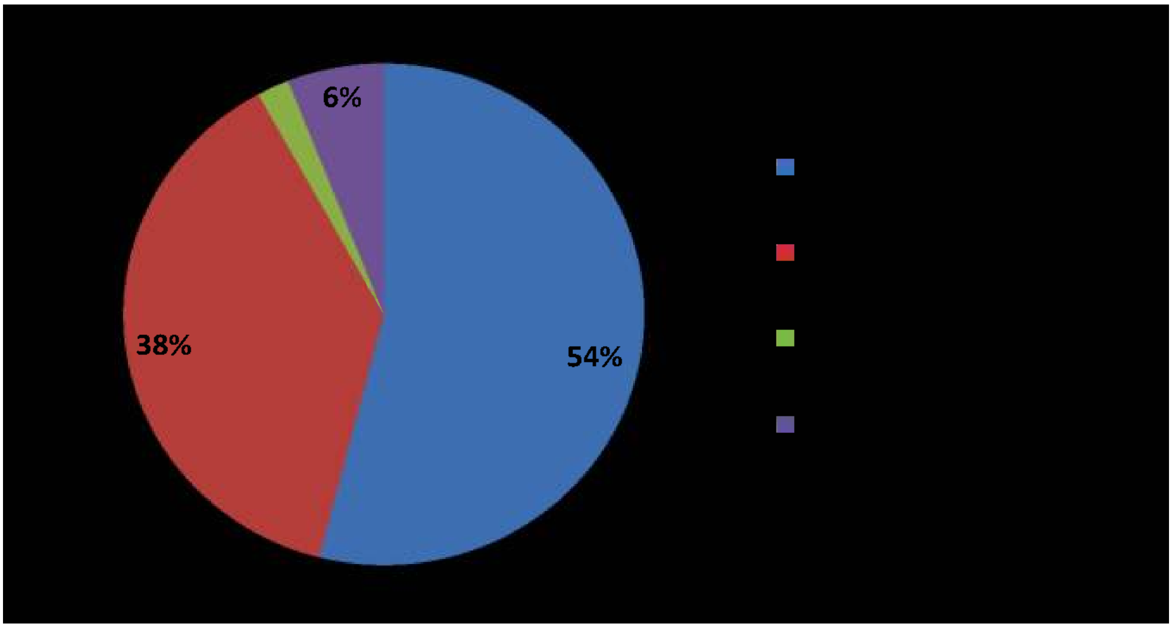


During the last 12 months, 3% (n=3) of women indicated that they had been coerced by health care workers to have an abortion because of their HIV-positive status.

84 women who had (ever rather than in the last 12 months) been pregnant were asked about access to services to prevent mother-to-child transmission. Of these, 45 women (54%) indicated that they had received ART. Some 6% (n=5) indicated that they did not know that such treatment existed or that they did not have access to this treatment (2%, n=2). The remaining 38% (n=32) indicated that hat they were not HIV-positive while pregnant (**Chart 34**).

Of the 45 women who indicated in the previous question that they received ART during a pregnancy, 84% (n=38) reported that were also given information about healthy pregnancy and motherhood in order to prevent mother-to-child transmission; while 7 women (16%) reported that they were not given this information.

Chart 34: ART during pregnancy, women, n = 84



Section 4: Barriers to accessing HIV testing, and treatment and care

In the Estonian study, additional questions were included to identify barriers faced by people when accessing HIV testing and, after a HIV-positive diagnosis, treatment and care. These questions were asked of 87 respondents, 56% of whom were men, and 43% women. Thirty-one percent (31%) had lived with HIV 1-4 years, 36% for 5-9 years, and 28% 10-14 years.

4.1 Barriers to accessing HIV testing

Chart 35 shows that 40% (n=35) underwent HIV testing within 3 months of first thinking about it with 69% (n=60) undergoing HIV testing within one year. However, 21% (n=18) waited between 1-2 years and a further 10% (n=)) waited 2-5 years.

Chart 35: Length of delay before testing for HIV

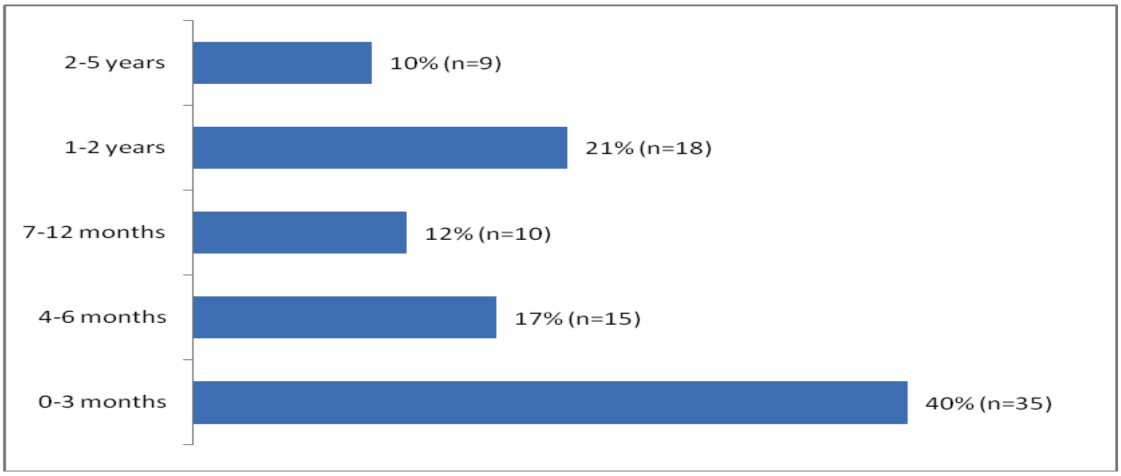
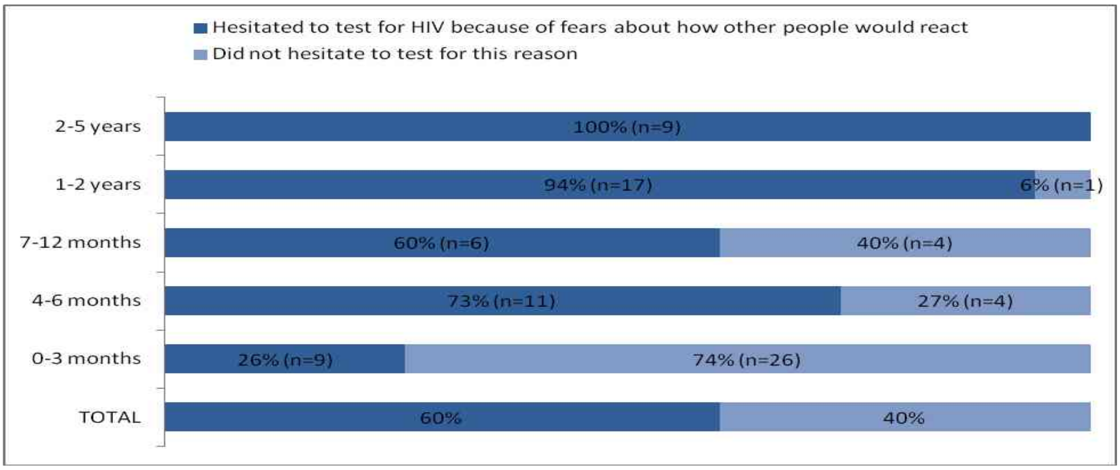


Chart 36 shows the correlation between fears about how other people (for example, friends, family, employer or community) would respond to a HIV-positive test result and hesitating to undergo a HIV test. In total, 60% (n=52) reported hesitating to get tested; while, 40% (n=35) reported not hesitating for this reason.

Of those who tested within three months, 26% reported that they were afraid of the reactions of other people. By contract, a majority (greater than 60% in all groups) of those who waited at least four months and up to 5 years to take a HIV test reported that this fear made them hesitate to test. The percentage rose sharply for those who waited two years (94%) and to 100% of those who waited for two to five years. These data provide a strong indication that anticipation of stigma is a factor that leads significant numbers of people to delay HIV testing.

Chart 36: Delays in HIV testing and fear of the reactions of other people



4.2 Time lapse after HIV-positive diagnosis and seeing a health professional

Chart 37 shows the time lapse after HIV-positive diagnosis and seeing a health professional for HIV infection. Two-fifths (41%, n=35) starting seeing a health professional fairly quickly (within three months of diagnosis); while another 27% (n=23) waited 4 months to one year. However, for almost one-third of the respondents (31%, n=27), the time between receiving test results and starting to see a health professional for HIV infection was from one to more than 5 years. One of the respondents (1%) has yet to start seeing a health professional for HIV care and treatment.

Chart 37: Time lapse after HIV-positive diagnosis and seeing a health professional for HIV infection

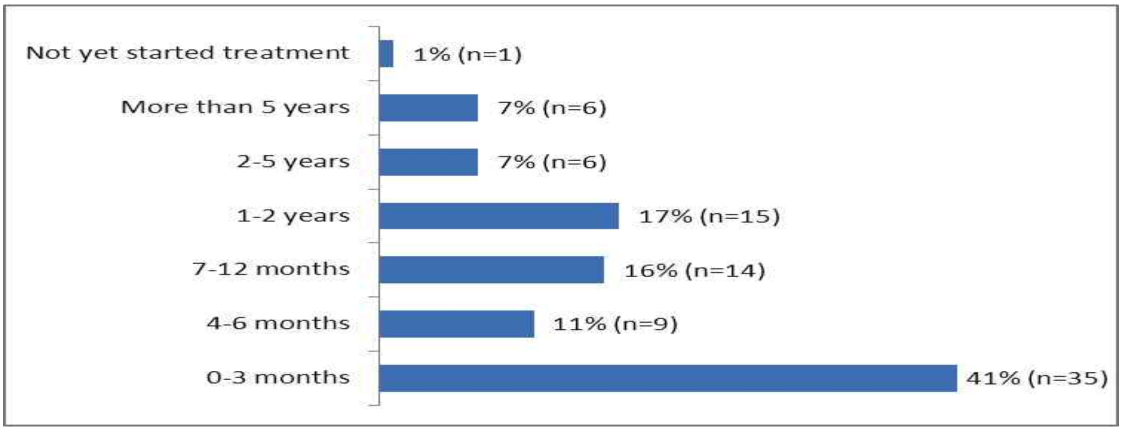
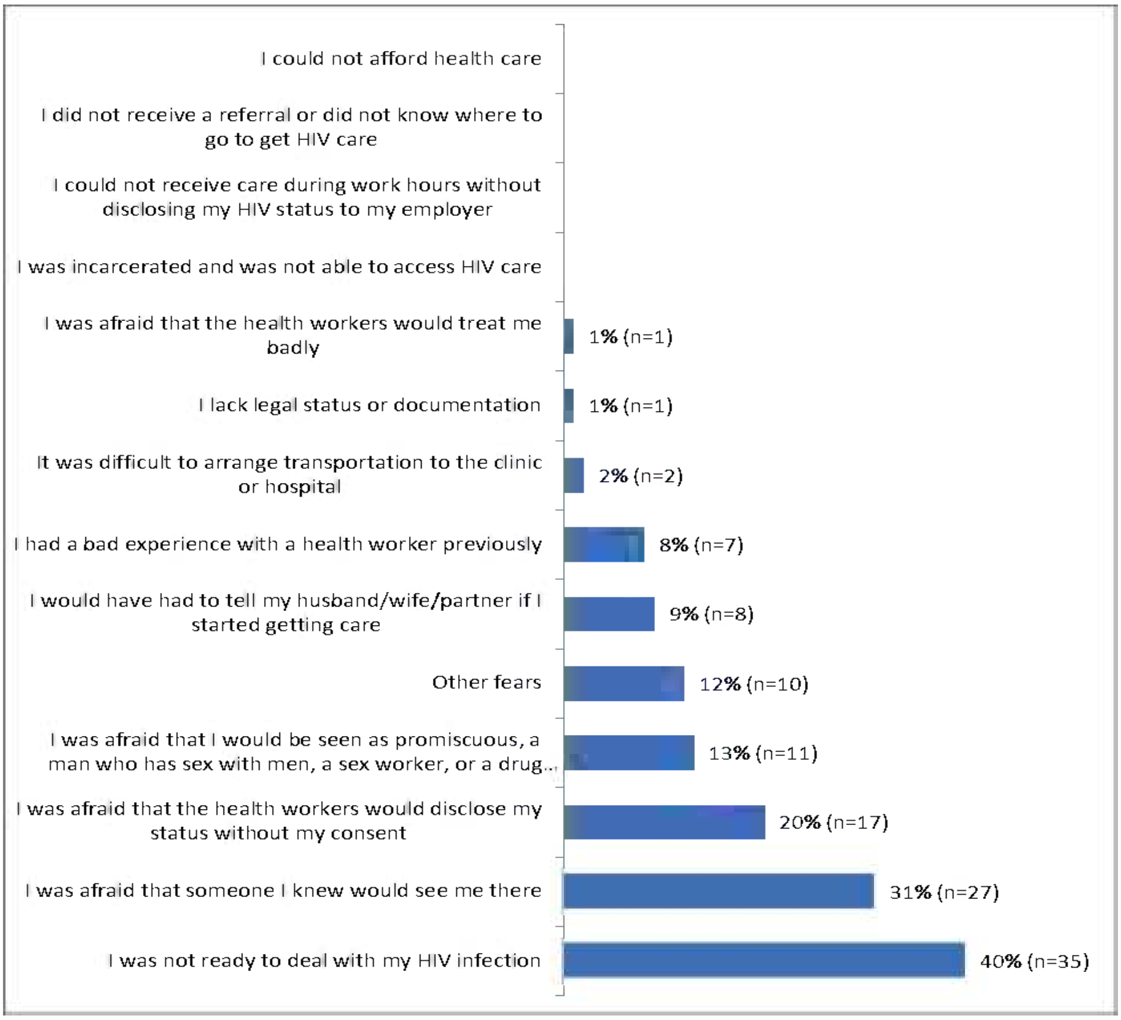


Chart 38 shows reasons reported by respondents for a gap in time between a HIV-positive test and starting to receive care. 40% (n=35) indicated that they were not ready to deal with their HIV infection; while 31% (n=27) feared that they might be seen by someone they knew if they went for medical care.

Fear of the quality of health care was cited as a reason for delaying receiving care. For example, 20% (n=17) of respondents reported fearing that health workers would disclose their status without consent, 8% (n=7) had previously had a bad experience with a health worker, and 1% (n=1) feared that a health care worker would treat them badly.

While a few respondents said that they had transportation difficulties (2%, n=2) or lacked legal status or documentation (1%, n=1), no respondents said that they did not seek medical treatment because they were internees, they could not afford the treatment or they did not know where to get the treatment.

Chart 38: Reasons why treatment was delayed, n = 87



Section 5: Specific Issues – Qualitative Data

In the Estonian study, respondents were provided an opportunity to provide qualitative information on a number of issues, including access to health services, information disclosure and breaches of confidentiality, access to ART, and children of HIV-positive parents. Although most respondents reported no problems, some comments show that bottlenecks remain.

5.1 Access and quality of health services

Respondents reported problems at each point of the care process as well as the acceptability (standard) of care that they received;. 31 respondents mentioned that queues for doctor's appointment are very long; while 16 respondents complained about the ongoing lack of information with the 'bad' attitude of doctors being mentioned by respondents. Specific comments included:

1. Doctors are too busy and because of that there are long queues (months long), or you must pay for the visit. For example:
    - *I was waiting for three months to get a doctor's appointment number!*
    - *If you miss the appointment you must wait another half a year.*
    - *Incompetence of doctors; long queues in infectious diseases departments.*
    - *You must wait your turn for very long time. If you happen to miss the appointment, then you have to wait another half a year again.*

2. If the disease is diagnosed there is no more support and no information about what to do next. People need information about how to live and how to treat themselves; they need psychological help and consultation. For example:
    - *I did not get any information (not even then when the disease was diagnosed).*
    - *Doctors did not consult, little information, I have to pay a visit fee.*
    - *Diagnosing and tests took place without my consent, nobody told me how to live with it (HIV).*
    - *They take blood samples, diagnose and nothing will be explained.*
    - *The problem is that there are no consultations after testing.*
    - *Not enough information! I would like to get psychological help.*

3. Medical staff's attitude is derogatory or even discriminatory. For example:
    - *It is very difficult to get doctor's appointment (long queues and visit fees). No*

  consultation before and after the test. Doctors' attitude is patronizing.
- *Doctors have sometimes very bad attitude.*
- *Long queues and brutal doctors.*
- *It is difficult to reach a doctor, long waiting lists, after a person finds out that she/he is HIV-positive little support is provided.*
- *My doctor did not tell me how to cope with the disease, what kind of treatment I may get; I have very little information about people who are living with HIV and about how others feel about these people. A lot of discrimination and beastly attitude.*
- *After I was diagnosed HIV-positive doctors forced me to terminate my pregnancy: they affected me psychologically.*

4. Thereafter it is even more difficult to obtain treatment because doctors do not want to deal with HIV-positive patients. For example:
   - *Specialists do not want to take tests (e.g. dermatologist) because of HIV.*

Respondents were asked: What would you recommend to change the situation? Responses included voluntary HIV testing with quicker results; doctor's appointment should be available; and blood should not be taken without the consent of the patient, she/he should know about it. For example:

- *Results of anonymous test should arrive quicker.*
- *Taking blood for HIV test without consent of the patient.*
- *It would be necessary to notify prior taking HIV test.*

Though some respondent’s expressed the following views:

- *Testing should be compulsory.*
- *Examination should be forcible.*

People suggest that there should be more HIV testing centres, including providing rapid testing and medical staff should have better communication skills.

Some respondents face considerable levels of fear, or think that it is senseless to go to the doctor. For example:

- *No veins and I am simply scared.*
- *I did not want to give a medical analysis (I was afraid to finding out about diagnosis).*
- *I think that it is senseless to visit a doctor because the disease is incurable.*

5.2 Information disclosure and breaches of confidentiality

114 respondents (38%) feel more or less that their HIV status is not anonymous and their data is not confidential. For example:

- *Confidentiality is not guaranteed. I called to the doctor's office to find out about the result of the analysis, and the doctor told everything about the results (saying my last name), but my neighbour sat in my office at that time. There was a conflict.*
- *I have often experienced it. No confidentiality. When you sit in the queue everything is already clear. Everything that is told in the doctor's office is audible in the corridor. Doctors talk about the status.*
- *The medical files of prisoners are accessible for the prison staff as well as for prisoners.*
- *My parents were informed by telephone, without my knowledge.*
- *After they become aware of my HIV status, their (other people's) attitude towards me will change.*

People want that only their doctor knows about their HIV-positive status and that the information can only be disseminated to third parties with their consent. For example:

- *I do not want that the information spreads outwards the cabinet.*
- *I do not want that the whole polyclinic and hospital knows about my HIV-positive status.*
- *I live in a small town and my HIV status will be made public!*

Some of the respondents suggested that medical staff should be liable for breaches of confidentiality. For example:

- *Doctors are not afraid to disclose HIV status. Doctors prosecution according to the law.*
- *Doctors do not take confidentiality seriously. Doctors' liability should be higher, distribution of HIV-positive patients information should be prohibited.*
- *Doctors talk among themselves about HIV-positive people Doctors should be prohibited to communicate such information to each other.*
- *It is necessary to complement the laws and to make sanctions stricter to avoid HIV-status information leakage.*
- *My HIV status was disclosure to all relatives. But it is not punishable and I am the one who suffers.*
- *A lot of people will forward the information about my status without my consent. There should be a law that allows the criminal proceedings. In a public health centre the doctor enters your personal code into the computer, for example, an eye doctor - it is not necessary that she/he knows about my status.*

Respondents are living in fear that third parties to whom the information is not required (e.g. public servants, medical staff who do not deal directly with the patient), or whose attitude may change when HIV-positive status is published (neighbours, relatives) will find out about their HIV-positive status. Respondents think that HIV-positive people should be helped and assisted in standing up for their rights more often.

5.3 Access to antiretroviral therapy

Respondents complained that it is very difficult to get a doctor's appointment (it takes a long time); doctors are accused of incompetence and lack of tolerance; and a fee must be paid. For example:

- *We pay the visit fees in order to get the ARV tablets.*
- *Everything is given in a row, needed medicines are selected infrequently.*
- *Few doctors, I have to wait long time! Poor medical qualification.*
- *Long queues, if you want to see a specialist.*

In prisons treatment is problematic because:

- *They do not give pills on time or they forgot to give them at all.*
- *In prison you can not take additional vitamins and food is not nutritious enough.*

Some people complained about their ART, either the period of time of treatment is needed, or the side effects. For example:

- *During pregnancy I did not see any problems but do not want start with it as it is for lifetime.*
- *If I do not need, I do not want to use it because it is for lifetime.*
- *I am afraid of side effects.*
- *Do not like it, it is for lifetime.*
- *I do not want to. I feel weakness.*
- *I'm afraid that I may start to drink (I have heard a lot of negative about ARV therapy). It seems to me that if do not drink the medicine, it means that I am healthy.*

Respondents feel that there is also too little information about ART: *'HIV-positive people have no information about ARV treatment'*; and people start with the treatment too late: *"(---) in Estonia ARV treatment starts very late, when CD is lower than 400, it should be provided earlier."*

5.4 Children of HIV-positive parents

In terms of having children and preventing mother-to-child transmission, many responses reveal that HIV-positive people, medical staff and people in general should be better informed. While some of the respondents think that there are no problems; some respondents think that there is a risk though if medical prescriptions are followed and if people are sufficiently informed, then HIV-positive parents can have healthy children: Views included:

- *HIV-positive parents can also have healthy children.*
- *If you follow all medical prescriptions, and all the precautions, you can(have children) .*
- *Of course there is a risk but it is very small.(*
- *Yes, HIV-positive parents should have children.*
- *If you use medicines on time then there is no problem.*
- *Not against it, if you follow all the precautions.*
- *If you follow all the precautions. Under doctors' control.*
- *Possible, but with caution (all tests must be taken).*
- *The doctor's instructions should be followed.*
- *90% of the babies are born healthy.*
- *It is possible that HIV-negative partner gets infected, both partners must be informed.*
- *It is unsure if the child will be born healthy. It is necessary that doctors monitor a mother during pregnancy.*

People have also mentioned that in Estonia it is not possible to wash sperm.

There were mixed views and feeling about reproductive health issues for HIV-positive people. For example:

- *A HIV-negative woman is not ready to give birth to HIV-positive man's child.*
- *I decided not to have children!*
- *HIV-positive people should not have children because those children have no future.*
- *The girls who are HIV-negative do not want to have children with me.*

Medical staff have treated HIV-positive people in ways that have traumatized them or have shown discriminatory attitudes. For example:

- *Repulsive behaviour of doctors (gynaecologists).*
- *Discrimination by medical staff Task: people should be enlightened correctly about HIV.*
- *Sometimes the doctors refuse to receive baby delivery.*
- *Sometimes the doctors refuse to receive HIV-positive women's baby delivery.*

- *Bad attitude of the medical staff.*
- *Provide false information about reproductive options.*
- *My girlfriend was forced to make an abortion if the pregnancy tests showed that she is HIV-positive. It was said that not even think about having children in the future and I suspect that they caused a physical trauma to my girlfriend.*

Respondents admit their fears: For example

- *Yes, I feared of the child's sake, I was afraid that she/he may be ill.*
- *Despite my fear that the child may be ill I do not trust doctors.*
- *Problems with my internal fears.*

Conclusions

The study found that show that HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services in Estonia. The findings of the experiences of people living with HIV by area are outlined below.

Exclusion

- The majority of respondents (63%) reported that they had been gossiped about at least once in the last year with 39% indicating that it occurred, in whole or in part, because of their HIV-positive status
- Significant percentages of respondents reporting having been verbally insulted/harassed/threatened (39%), physically assaulted or threatened (24%), and/or physically assaulted (22%) at least once in the last year. Of these, 31% indicated being insulted/harassed/threatened, physically assaulted or threatened (12%), and/or physically assaulted (10%) during the last 12 months, in whole or in part, because of their HIV-positive status.
- Over 60% of respondents feel that HIV-related stigma and/or discrimination is due to people not understanding how HIV is transmitted or are afraid of infection through casual contact.

Access to work and health and education services

- Over one quarter of respondents (n= 78) had been forced to change residency/refused accommodation in the last year with 10% thinking the reason was HIV-positive status-related.
- Nearly 30% (n=38) reported having lost a job or another source of income in the last 12 months.
- 25 respondents (8%) report being denied health services, including dental care, at least once in the last 12 months.
- Some 4% (n=12) of respondents have been refused family planning services during the last 12 months; of whom half were women (n=6).
- Some 2% (n=6) of respondents had been denied sexual and reproductive health services during the last 12 months; half of whom were women (n=3).
- 11 respondents (4%) indicated that they had been dismissed, suspended, or prevented from attending an educational institution in the previous 12 months.
- 4 (1%) respondents had experienced that their children have been dismissed, suspended or prevented from attending an educational institution because of the respondent's HIV status during the last 12 months.

Estonia

Internalised stigma and fears

- Internalised stigma was prevalent: over 60% feel guilt, 57% blame themselves, 42% feel ashamed, and over 33% report low self esteem.
- 10% of respondents reported feeling suicidal with women reporting more suicidal thoughts than men (15% to 7%).
- The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (25%), not to marry (13%) and to isolate themselves from friends and relatives 812%).
- Internal stigma affects:
    - access to health care: 17% (n=51) avoided going to a local clinic when they needed care, and 11% (n=34) avoided going to hospital.
    - study and employment: 8% (n=23) withdrew from education or training, 7% (n=21) decided not to apply for a job or a promotion because of their HIV status and 4% (n=13) gave up their job.
- Overall, 41% of respondents feared being gossiped about; significantly higher levels of fear than verbal insult (29%), physical harassment and/or threat (20%), and physical assault (17%).

Rights, laws and policies

- The Estonian Equal Treatment Act was known to 38% of respondents (n=113); of whom, 38% (n=43) had read or discussed it.
- During the previous 12 months, 34% (n=103) of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- The most frequent violation reported by 34% of respondents (n=101) was having been forced to submit to a medical procedure (including HIV testing).
- Twenty respondents reported that that they experienced a rights violation within the previous 12 months, of whom three had sought legal redress; of the 17 respondents who did not, the most common reason cited (50%) was belief that the outcome would be unsuccessful.

Effecting change

- In the previous 12 months, over 60% of respondents provided some form of support to HIV-positive people; while nearly 20% had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV.
- During the last 12 months, 29% (n=86) of the respondents reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against him or her.
- Respondents who belonged to a network of people living with HIV (36%) and those

with a technical college or university education (39%) were more likely to report that they had confronted someone who was stigmatizing them.

- Overall, 68% of the respondents knew of an organization or groups providing support to those experiencing stigma or discrimination with networks of people living with HIV the most frequently cited (58%); followed by PLHIV support groups (44%).
- Fifteen respondents (5%) indicated that they had sought help from an organization for problems related to stigmatization or discrimination.
- 62% of respondents reported having provided some form of support to other people living with HIV in the previous 12 months with emotional support (95%) being the most common type of assistance rendered.
- Over one third of respondents (34%) reported being a member of a support group and/or network of people living with HIV.
- Nearly 20% (n=59) had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV in the previous 12 months.
- Only 3% of respondents had been involved in efforts to develop HIV-related legislation, policies or guidelines.
- Over 80% of respondents felt unable to influence policies, laws and programmes at either national or local levels.
- In terms of the most important thing organisations should do to address stigma and discrimination, more than 40% cited advocating for the rights of all people living with HIV;

Testing and diagnosis

- 43% (n=130) reported taking a HIV test just to know their status.
- 7% (n=21) were referred for HIV testing when already symptomatic.
- In terms of coerced testing or without a person's consent:
    - 21% of respondents were tested while in prison (n=64), equalling 42% of prisoners in the sample discovering their HIV-positive status while in prisons; and
    - 7% of respondents were tested during the process of other medical procedures (n=21).
- Overall, slightly less than two-thirds of the respondents indicated that their HIV test was completely voluntarily with 10% reporting being forced to take a HIV test. More respondents who were recently diagnosed reported that they had undergone HIV testing voluntarily.
- Respondents with the highest reported levels of food insecurity were more likely to have been coerced to test (18% (n=10) compared to 10% (n=16) with no food insecurity) or tested without their knowledge (27% (n=15) compared to 13% (n=21) with no food insecurity).
- Nearly a third of respondents received both pre- and post-test counselling; however,

just over a third received no counselling at all, while nearly a third received only post-test counselling, and 2% received only pre-test counselling.

Disclosure and confidentiality

- High levels of disclosure by respondents included to: health care workers (77%), other HIV-positive people (72%), spouses or partners (67%), and other adult family members (61%), injecting drug partners (57%), and social workers and other counsellors (51%);
- 5% of respondents have not disclosed to their spouse or partner, and 7% have not disclosed to injecting drug partners.
- Many respondents had not disclosed their HIV status to their children (45%), or to their employers (28%) or co-workers (27%).
- Approximately 80% of respondents reported that they had not felt pressured to disclose their HIV status by others.
- 22% of respondents reported that a health care professional had told other people about their HIV status without their consent.
- Nearly half of respondents indicated that they do not know if their records are kept confidential; while it was clear to 30% of respondents that they were not being kept confidential.
- Health care workers reported as having the highest levels of discriminatory reactions to learning of a respondent's HIV status (19%).
- Respondents reported varying reactions from spouses and partners to learning of their HIV status, with 10% saying that their spouses or partners reactions were discriminatory or very discriminatory and 43% saying that their spouses or partners were supportive or very supportive.
- Approximately half of respondents described disclosing their HIV status as an empowering experience.

Treatment

- Only (7%) described their health as 'excellent' or 'very good'; two thirds of as 'fair' or 'poor', and 27% as 'good' with the longer respondent has lived with HIV the more likely he or she is to describe health status as 'fair' or 'poor'.
- 59% of respondents were taking ART with 94% indicating that they could access ART if needed.
- 12% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections, and 64% reported having access to these medications, if needed.
- 66% of respondents had discussed HIV treatment options and 40% had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children

- More than half of respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
- 17% (n=50) reported that they have been advised by a health care worker not to have a child since their diagnosis with women significantly more likely to report this.
- Ten respondents (3%), of whom 8 were women and 2 were men, reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis, all of whom identified as current or former people who use drugs.
- Seven respondents (2%) reported that their ability to obtain ART was conditional on using certain forms of contraception.
- During the last 12 months, coercion by health care workers because of HIV-positive status was reported by 5 women (abortion), 4 women (method of giving birth) and 2 women (infant feeding practices).
- In relation to PVT, of 84 women who had been pregnant:
    - 54% (n=45) indicated that they had received ART, 6% (n=5) 84 women who had been pregnant indicated that they did not know that such treatment existed or that they did not have access to ART (2%, n=2).
    - 84% (n=38) reported that were also given information about healthy pregnancy and motherhood in order to prevent mother-to-child transmission; though 7 women (16%) reported that they were not given this information.

In terms of the qualitative interviews, the following issues were addressed:

Barriers to accessing HIV testing

- 40% of 84 respondents underwent HIV testing within 3 months of first thinking about it with 69% undergoing HIV testing within one year; however, 21% waited between 1-2 years and a further 10% waited 2-5 years.
- Anticipation of stigma from the data appears to have led significant numbers of people to delay HIV testing. For example, 60% reported hesitating to get tested because of fears about how other people (for example, friends, family, employer or community) would respond to a HIV-positive test result.

Time lapse after HIV-positive diagnosis and seeing a health professional

- Two thirds of respondents started seeing a health professional within one year of diagnosis; however, almost waited from one to more than 5 years.
- 40% indicated that they were not ready to deal with their HIV infection; while 31% feared that they might be seen by someone they knew if they went for medical care.

- Fear of the quality of health care was cited as a reason for delaying receiving care. For example, 20% (n=17) of respondents reported fearing that health workers would disclose their status without consent, 8% (n=7) had previously had a bad experience with a health worker, and 1% (n=1) feared that a health care worker would treat them badly.

Access to health services

- Problems begin with doctor's appointment and continue to an ongoing lack of information and health professionals' attitudes both discriminatory and refusal to treat.
- In terms of changing this situation, respondents recommended voluntary HIV testing with quicker results; doctor's appointment should be available; and blood should not be taken without the consent or knowledge of the person concerned.

Information disclosure and breaches of confidentiality

- 114 respondents (38%) feel more or less that their HIV status is not anonymous and their data is not confidential.
- In terms of changing this situation, respondents recommended that only their doctor knows about their HIV-positive status and that the information can only be disseminated to third parties with their consent, suggesting that medical staff should be liable for breaches of confidentiality.

Access to antiretroviral therapy

- Respondents complained that it is very difficult to get a doctor's appointment and that to see a doctor involves a fee; also doctors are accused of incompetence and lack of tolerance.
- Respondents complain about or are afraid of ART-related side effects, and have negative perceptions about ART being life-long.
- Respondents feel that there is insufficient information about ART.

Children of HIV-positive parents

- In terms of having children and PVT, many respondents feel that HIV-positive people, medical staff and the general public should be better informed.
- There were mixed views and feeling about reproductive health issues for HIV-positive people. People acknowledge that the risk of mother-to-child transmission can be minimized with ART; respondents worry about having children.
- Medical staff have treated HIV-positive people in ways that has traumatized them or has shown biased attitudes

Recommendations

The following recommendations are made in light of:

- high levels of stigma and discrimination in a number of areas, including exclusion; access to residency/accommodation, employment and health care;
- high levels of internalized stigma; and
- low levels of perceived ability to effect change reported by people living with HIV in Estonia involved in this study.

The overall recommendation derives from the facts that among the sample there was low socio-economic status, including significant percentages of respondents reporting low levels of education and employment, as well as internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community (with reported examples of stigmatising and discriminatory treatment), and 10% of respondents reported feeling suicidal. As such, psychosocial and socioeconomic support must clearly be a priority for the Estonian Network of PLHIV, civil society, the National AIDS Programme and the Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities for people living with HIV to become peer educators, capacity and network building, counselling, training, and income generation.

Other specific recommendations directed to the Estonian Network of PLHIV, civil society, the National AIDS Programme and the Government are outlined below.

Estonian Network of PLHIV

- Disseminate the findings of this study to the Government, National AIDS programme, civil society, UN agencies and donors.
- Advocate for the rights of all people living with HIV, including key populations, and advocate against and challenge rights violations.
- Intensify education efforts with people living with HIV on positive health, dignity and prevention.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to the general public.
- Encourage and build the capacity of people living with HIV to advocate for their rights; be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes; and to provide support and assistance to people living with HIV individually, and

through support groups and other local organisations.

- Empower HIV-positive people to know and assert their rights.
- Advocate for the inclusion of more people living with HIV in policy-making fora and in the development and drafting of relevant legislation.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, including key populations, and in particular people who use drugs, current and former prisoners, and people with disabilities.
- Undertake further research into the underlying facilitators of disclosure of HIV status, including disclosure-related feelings of empowerment and stigma.

Civil Society

- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV and key populations.
- Advocate for the rights of all people living with HIV, including key populations.
- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.

National AIDS Programme

- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Given that there is a low level but consistent pattern of denial of the rights of people living with HIV in health care settings[24], including SRH rights[25]:

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[24] For example:

- 25 respondents (8%) report being denied health services, including dental care, at least once in the last 12 months.
- Internal stigma also affects access to health care: 17% (n=51) avoided going to a local clinic when they needed care, and 11% (n=34) avoided going to hospital.
- 34% of respondents (n=101) were forced to submit to a medical procedure (including HIV testing).
- In terms of coerced testing or without a person's consent:
    - 21% of respondents were tested while in prison (n=64), equalling 42% of prisoners in the sample discovering their HIV-positive status while in prisons; and
    - 7% of respondents were tested during the process of other medical procedures (n=21).

  - revise pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV, including PVT;
  - review and update, if needed, protocols to ensure they are rights-based and include pre-service training for health care workers as well as in-service training refresher courses for health providers, managers and other health facility staff, as well as strengthen supervision to foster non-judgmental and non-discriminatory practices towards people living with HIV; and
  - scale up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, across all locations.
- Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes[26].
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

- Just over a third received no pre- and post-test counselling, while nearly a third received only post-test counselling, and 2% received only pre-test counselling.
- 22% of respondents reported that a health care professional had told other people about their HIV status without their consent.
- Health care workers reported as having the highest levels of discriminatory reactions to learning of a respondent's HIV status (19%).

[25] For example:

- 4% (n=12) respondents have been refused family planning services during the last 12 months.
- 2% (n=6) respondents had been denied sexual and reproductive health services.
- More than half of respondents (53%, n= 156) indicated that they had never received counselling on their reproductive options since their HIV diagnosis with men significantly less likely than women to have received such counselling (38% compared to 53%).
- 17% (n=50) reported that they have been advised by a health care worker not to have a child since their diagnosis with women significantly more likely to report this, 28% (n=31), than men, 10% (n=19).
- Ten respondents reported that they had been coerced by a health care professional into being sterilized since HIV-positive diagnosis, all of whom identified as current or former people who use drugs.
- Seven respondents (2%) reported that their ability to obtain ART was conditional on using certain forms of contraception.
- Coercion by health care workers was reported by 5 women (abortion), 4 women in relation to the method of giving birth and 2 women in relation to infant feeding practices.
- In relation to eMTCT, 6% (n=5) of pregnant indicated that they did not know that such treatment existed or that they did not have access to this treatment (2%, n=2).
- Fear of the quality of health care was cited as a reason for delaying receiving care.

[26] See: http://www.srhhivlinkages.org/en/srh_and_hiv_linkages.html#53

- Undertake and/or support research to strengthen the evidence base, including:
- Studies on the denial of sexual and reproductive health services to people living with HIV.
- Associations between low income level and severe food insecurity, and positive experience of disclosure.

Government

- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically addresses HIV-related stigma and discrimination, requires informed consent for HIV testing, protects confidentiality and provides redress for breaches.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, including support for scaled up implementation of promising programmes.
- Include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.

Notes

Disclaimer:

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the national response to HIV.

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