



# People Living with HIV Stigma Index 2.0

Finland 2024

# Contents

<b>FIGURES</b> .....	<b>2</b>
<b>LIST OF ABBREVIATIONS</b> .....	<b>3</b>
<b>EXECUTIVE SUMMARY</b> .....	<b>4</b>
<b>1 INTRODUCTION</b> .....	<b>8</b>
1.1 WHAT IS STIGMA INDEX? .....	8
1.2 PROJECT EXECUTOR POSITIVISED BY .....	9
1.3 SOCIETAL AND EPIDEMIOLOGICAL SITUATION IN FINLAND .....	9
1.4 STIGMA AND DISCRIMINATION .....	10
1.5 PREVIOUS RESEARCH .....	11
<b>2 METHODOLOGY</b> .....	<b>13</b>
2.1 EXECUTION OF THE PROJECT .....	13
<b>3 RESULTS</b> .....	<b>16</b>
3.1 BACKGROUND DATA OF THE RESPONDENTS .....	16
3.2 DISCLOSING HIV-STATUS .....	17
3.2.1 <i>Experiences of disclosing HIV status</i> .....	18
3.3 EXPERIENCES OF STIGMA AND DISCRIMINATION .....	23
3.4 INTERNALISED STIGMA .....	24
3.5 INTERACTIONS WITH HEALTHCARE SERVICES .....	27
3.5.1 <i>Non-HIV related healthcare</i> .....	28
3.5.2 <i>Experiences of HIV treatment</i> .....	29
<b>4 DISCUSSIONS</b> .....	<b>33</b>
4.1 RESULTS AND RECOMMENDATIONS .....	35
4.2 LIMITATIONS OF THE STUDY .....	37
<b>REFERENCES</b> .....	<b>39</b>

## Figures

Figure 1: The experience of disclosing HIV status to close persons. ....	18
Figure 2: Support from close persons after disclosing HIV status. ....	19
Figure 3: The experience of disclosing HIV status to people not well known. ....	20
Figure 4: Support received from other people after disclosing HIV status. ....	21
Figure 5: The easing of the HIV status disclosure process over time. ....	22
Figure 6: The impact of internalized stigma. ....	25
Figure 7: The impact of HIV status on various life aspects in the past 12 months. ....	26
Figure 8: Trust in medical confidentiality. ....	29

## List of abbreviations

**HIV** – Human Immunodeficiency Virus

**AIDS** – Acquired Immune Deficiency Syndrome. Acquired in this context means the opposite of congenital or accidental.

**MSM** – Men who have sex with men

**PLHIV** – People Living with HIV

**GNP+** – Global Network of People Living with HIV

**ICW** – International Community of Women Living with HIV

**IPPF** – International Planned Parenthood Federation

**UNAIDS** – The Joint United Nations Programme on HIV and AIDS



**Positiiviset ry HivFinland rf**

[positiiviset@positiiviset.fi](mailto:positiiviset@positiiviset.fi)

[www.positiiviset.fi](http://www.positiiviset.fi)

## Executive Summary

### Purpose of the project

The stigma associated with HIV affects the lives of people living with HIV (PLHIV) and their loved ones in many ways, as well as HIV prevention efforts. The stigma experienced by people living with HIV causes a mental burden, which also affects wellbeing and quality of life. Often, PLHIV want to keep their HIV status a secret, and the fear of their infection being revealed may cause fear and anxiety. Stigma is one of the main reasons why people living with HIV may have negative feelings about themselves in relation to their HIV diagnosis (internalised stigma). Additionally, HIV-related stigma and discrimination have been identified as one of the greatest challenges in preventing new HIV infections. All efforts aimed at preventing new HIV infections require a balance between reducing stigma and normalising HIV. (THL 2017, Nobre 2018, Babel et al. 2021.)

It is impossible to develop effective methods to combat stigma unless we understand how stigma manifests in people's everyday lives. People Living with HIV Stigma Index is an international project developed by four international actors (GNP+, ICW, IPPF, and UNAIDS). It has now been implemented in Finland for the first time. The Stigma Index has been developed and is implemented by people living with HIV. The Stigma Index enables the measurement and description of the stigma and discrimination experienced by people living with HIV in various life situations in Finland. The main goal of the project was to advocate for and to promote the fundamental human rights and the realisation of a dignified life for people living with HIV by collecting data to support advocacy work. Additionally, the aim was to highlight societal norms and structures that impact the quality of life for people living with HIV in Finland. The execution of the project in Finland was carried out by Positiiviset ry which is the only patient organisation for people living with HIV in Finland.

### Methods

The study was conducted using structured interviews following the standardised PLHIV Stigma Index 2.0 questionnaire. A participatory research approach was employed as people living with HIV interviewed other people living with HIV. Additionally, the interview often served as a peer-supportive encounter and a source of strength for the respondents. There were 9 volunteer interviewers, and they were trained to conduct the interviews. The respondents were recruited by Positiiviset ry. The interviewers also recruited respondents themselves. The respondents were not purposely selected. Anyone could participate if they met the study criteria (over 18 years old, able to speak Finnish, Swedish, Russian, or English, provided informed consent, living with HIV and having received an HIV diagnosis over a year ago).

The interviews used as data for the study were conducted between October 2021 and October 2022. A total of 53 interviews were conducted. The interviews were carried out primarily as face-to-face interviews, but a few (6) were conducted remotely using online video connection. The COVID-19 pandemic posed significant challenges to the data collection, making it difficult to recruit respondents and extending the timeframe for completion of the study in 2022. In addition to the structured interviews, 12 semi-structured in-depth interviews were conducted with selected respondents using open questions. This was done to get more comprehensive information and understanding on people's experiences. The participants for in-depth interviews were recruited from the pool of respondents who took part in the quantitative part of the research and based on their willingness to participate in an in-depth interview.

## Results

The total number of respondents was 53, of whom 55% were men, 40% were women, and 3 respondents indicated that their gender was something other than woman or man. Most (62%) were middle-aged, between 40 and 59 years old. The median age was 50 years. Nearly half (47%) had a higher education level, and 30% had vocational education. Of the respondents, the majority (71%) were employed. Additionally, the majority (76%) of respondents had been aware of their HIV status for over 10 years, with a median of 14 years. Over half (58%) of the respondents were in a partnership or sexual relationship at the time of the interview. One-third (30%) of the respondents had a child or children who were dependent on them.

**Disclosing HIV status.** A vast majority of the respondents had disclosed their HIV status to close people, such as their spouse or partner (84%) or friends (83%). Some had experienced situations where their HIV status had been disclosed without their consent. For example, 36% of those whose co-workers knew about their HIV status indicated disclosure had taken place without their consent. Overall, disclosing their HIV status to close people had been a positive experience for half (50%) of the respondents, and the majority (70%) felt they received support from them after sharing their HIV status. Disclosing their HIV status had become easier over time for 43% of the respondents.

**Experience of stigma and discrimination.** In the Stigma Index study experiences were reported either from the last 12-month-period or before. The results show that experiences of stigma and discrimination were relatively common over 12 months ago. The most common form of perceived stigma and discrimination among the respondents was verbal harassment. 31% of the respondents had experienced verbal harassment. Almost a quarter (24%) of the respondents had experienced people gossiping or expressing discriminatory remarks about them due to their HIV-positive status.

**Internalised stigma.** Internalised stigma was the most experienced form of stigma in the last 12 months. Among the respondents, internalised stigma particularly influenced their own behaviour and choices. A large majority of the respondents (74%) found it difficult to disclose their HIV status to other people. In the last 12 months, 18% of the respondents had chosen not to engage in sexual activities, 11% had chosen not to seek healthcare, 10% had decided not to participate in social events, 8% had chosen not to apply for a job, and the same percentage (8%) had chosen to distance themselves from their family and/or friends because of their HIV status.

**Interaction with healthcare.** A majority (60%) of the respondents reported disclosing their HIV status whenever they sought healthcare unrelated to HIV. Almost as many (57%) trusted that their HIV-related medical records were kept confidential by healthcare personnel. However, 17% of the respondents were certain that this was not the case. HIV-related stigma and discrimination were experienced more in healthcare unrelated to HIV than in HIV-related healthcare. 16% of the respondents had experienced situations where healthcare staff, for example, tried to avoid physical contact with the patient or took special precautions such as excessive protective measures.

## Conclusions & recommendations

People living with HIV in Finland face stigma and discrimination. The persistence of stigma is rooted in people's prejudices and fears, as well as in societal structures that perpetuate stigma. Consequently, stigma is used as a means of exercising power.

Even though humane social services and healthcare should be available for everyone, HIV-related stigma remains common in these settings. Seeking healthcare can cause worry and stress for people living with HIV who have previous experiences of being treated inappropriately. It is self-evident that PLHIV require medical care throughout their lives, not just due to HIV-related issues. It is unacceptable that the stigma associated with HIV prevents these individuals from seeking healthcare or fearing the disclosure of their status deters them from trusting healthcare professionals.

HIV medication maintains the health of a person with HIV and keeps the viral load undetectable. Undetectable viral load prevents HIV from transmitting. Although people living with HIV can lead fulfilling lives today, peer support and sharing common experiences remain important. The publication of research project results like the Stigma Index can, in the best case, support the wellbeing of people living with HIV,

encourage them to engage in peer activities, and promote HIV prevention through increased knowledge. Based on the results of the Stigma Index study, recommendations have been made to improve the situation.



# 1 INTRODUCTION

## 1.1 What is Stigma Index?

How do people living with HIV get on? What is it like to live with HIV in Finland? What kind of stigma or discrimination do people experience due to HIV? These are some of the questions for which answers were sought through the study conducted by Positiiviset ry, using The People Living with HIV (PLHIV) Stigma Index study developed by international organisations.

The People Living with HIV Stigma Index is a standardised research method aimed at providing information on the stigma and discrimination faced by people living with HIV. The study seeks to expand understanding of the types of stigmas and discrimination experienced by people living with HIV in different countries. Research data from various countries also helps organisations and associations working with HIV issues in their efforts. The Stigma Index study results can be of help when striving to generate concrete measures and recommendations to reduce stigma and discrimination faced by people living with HIV. The goal is to ensure the realisation of the human rights and basic rights of people living with HIV.

The Stigma Index study was developed to offer necessary information and proof that could be used to defend the rights of people living with HIV. It has been developed by people living with HIV and it is carried out by people living with HIV. The organisations behind the Stigma Index study are the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW), UNAIDS, the Joint United Nations Programme on HIV/AIDS (UNAIDS), and the International Planned Parenthood Federation (IPPF). IPPF was only involved in the development of the first version.

The Stigma Index study was first conducted in 2008. It has been implemented in over a hundred different countries, with more than 100,000 people living with HIV participating in the interviews. Ten years later, in 2018, a new version of the study was released, in which the changes in the development of the HIV epidemic and the global situation were taken into consideration. The revised version is called PLHIV Stigma Index 2.0. Furthermore, in 2020, a standardized methodology was introduced, the use of which improves the comparability of results in different contexts and allows for long-term comparison. This was developed by the International Partnership of the PLHIV Stigma Index (GNP+, ICW, and UNAIDS). In Finland, the PLHIV Stigma Index 2.0 questionnaire was used but the implementation of the study does not conform to the standardised methodology introduced in 2020.

## 1.2 Project executor Positiiviset ry

The Finnish Stigma Index study was carried out by Positiiviset ry (HivFinland) (in Swedish HivFinland rf). It is an advocacy and peer support organisation for people living with HIV and their immediate family and friends. It is the only patient organisation for people living with HIV in Finland. The organisation serves everyone living with HIV and their loved ones. A majority of the board members are always people living with HIV, so the services are by and for people living with HIV. Executing the project involved both association staff and volunteers, as well as two persons employed to work on the study for a few months. One coordinated the interviews, and the other worked as a researcher, conducting in-depth interviews, and participating in writing reports.

## 1.3 Societal and epidemiological situation in Finland

By the end of 2022, 4,730 HIV infections have been reported in Finland. There are approximately 3,500 persons that are aware of their infection and are on HIV treatment. Finland records ca. 150-170 new HIV infections each year. In 2022, there were 274 new infections, which is an unusually high number. It can be attributed to the increase of infections discovered among foreign citizens living in Finland (228 cases) and their increase in proportion of the total of new infections (83%). The increased number of infections among foreign citizens is generally due to the large number of people who fled the war in Ukraine. Most people living with HIV were already aware of their infection before coming to Finland. New HIV infections among Finnish citizens remained at a low level (46 people). The main mode of HIV transmission in Finland is heterosexual sex. In 2022, 26% of the infections were transmitted through heterosexual sex, 17% through sex between men, 10% through drug injection and 1% from mother to child. In 45 % of the cases, the mode of transmission was unknown. (THL 2023a.)

The treatment of HIV in Finland is monitored, for example, with help of the HIV register. The register contains information on the quality, outcomes, and effects of the patients' treatment. The HIV register is also important for tracking the epidemic, as treatment coverage and success impact the spreading of infections. In 2022, an estimated 94 % of those living with HIV were aware of their status, and 92 % of them received HIV medication. Among those receiving medication, 94 % had good treatment outcomes. The internationally set targets are known as the 95-95-95 goals, aiming to that 95% of people living with HIV be aware of their infection, that 95% of those aware receive HIV medication, and that 95% of those on medication respond well to treatment i.e., show an undetectable viral load. WHO, UNAIDS, and ECDC actively monitor the progress towards these goals. (THL 2022)

Many European countries have specific constitutional provisions that guarantee non-discrimination for people living with HIV. In Finland, there is no HIV-specific legislation, and HIV status is not specifically mentioned in the Non-Discrimination Act. Section 8 of the Non-Discrimination Act prohibits discrimination based on age, origin, nationality, language, religion, belief, opinion, political activity, trade union activity, family relations, health status, disability, sexual orientation, or other personal characteristics (Non-Discrimination Act 2014/1325).

One significant factor contributing to stigma was at least partially corrected in the autumn of 2021. The criminal legal practice concerning HIV exposure was unclear in Finland until the Supreme Court (KKO) made a significant precedential decision in 2021 (KKO 2021:64). In its ruling, the Supreme Court considered that treated HIV does not transmit (U=U, Undetectable = Untransmittable). Therefore, the person was not guilty of a crime, even if they engaged in unprotected sex without disclosing their condition to their partner. There was no crime committed because the medication makes HIV transmission to the partner unlikely.

“The Supreme Court held that, given the HIV medication used by A, the low viral load in his blood and the circumstances of the crime, the HIV infection had been so unlikely that the requirement of Chapter 5, Section 1(2) of the Criminal Code that there was a risk of the crime being committed had not been met. The charge of attempted aggravated assault was dismissed. (KKO: 2021:64)”

#### 1.4 Stigma and discrimination

The HIV epidemic began in the early 1980s. Since the beginning of the epidemic, there have been numerous negative and false beliefs circulating and spreading about HIV, AIDS and people living with HIV and/or AIDS. Anyone, including people living with HIV themselves, may find it challenging to avoid being exposed to these beliefs and prevent them from affecting their self-perception. HIV-related stigma can be described as a process where people living with HIV are devalued compared to others. Stigma reinforces social inequalities, based particularly on gender, sexuality, and ethnicity. HIV-related stigma produces and perpetuates power imbalance and control. (Huotari 1999, Nikkanen & Järvi 2014)

Key population groups affected by HIV are those who are especially vulnerable to HIV infection and disproportionately impacted by it. These groups often remain underserved globally, and access to HIV treatment cannot always be guaranteed. Central groups of population include gay men and other men who have sex with men, transgender persons, sex workers, people who inject drugs, and individuals in prisons and closed institutions. In some cases, the terms “marginalised groups” and “key populations” are also used to refer to these groups (e.g. THL 2017)

From an intersectional perspective, stigma and discrimination are examined regarding how people living with HIV experience them in relation to their lifestyles or identities, such as gender. An intersectional approach highlights the intersecting layers of stigma and discrimination faced by different minority groups. (THL 2023b) Globally, many people living with HIV experience intersectional stigma and discrimination, leading to a significantly higher likelihood of ending up in discriminative situations and more frequent experiences of discrimination.

Prejudices and stigma can influence people's behaviour or deter them from taking certain actions. Internalised or self-stigma refers to people living with HIV internalising negative messages and stereotypes related to HIV and then applying these negative feelings to themselves. This internalisation can lead to feelings of shame, fear of disclosure, isolation, and despair. These feelings and emotions may, for example, prevent people from seeking HIV testing and treatment. Internalised stigma can also manifest as avoiding social or intimate contacts or refraining from seeking services out of fear of disclosure or discrimination. (Turan et al. 2017.)

Discrimination occurs when a person is treated worse than others based on certain personal characteristics. Discrimination is prohibited, for example, in non-discrimination laws, criminal laws, and international human rights agreements. HIV-related or HIV-status-based discrimination is often seen as the result of stigma. HIV-related discrimination refers to situations where individuals are treated worse than others because their HIV-positive status is known or suspected, or they are in other ways associated with people living with HIV. HIV-related stigma and discrimination can also be experienced by the partners or cohabitants of people living with HIV, or even healthcare personnel dealing with HIV treatment. HIV-related discrimination for instance occurs when people living with HIV are denied certain services, such as healthcare, due to their positive HIV-status.

Discrimination is a continuum of stigma. It involves unjust and unfair treatment based on an individual's real or perceived HIV status. Stigma and discrimination violate human rights and can occur on various levels: political, economic, social interaction, as well as psychological or institutional levels. (UNAIDS 2022.)

## 1.5 Previous research

In Finland, there are no previously published studies solely focused on HIV stigma. The most recent study conducted by Nuno Nobre in his doctoral thesis (Nobre 2018) addresses HIV stigma alongside the quality of life of people living with HIV. The conclusions of the study state that self-stigma significantly affects the

quality of life of people living with HIV in Finland, and to reduce it, comprehensive psychosocial interventions are needed.

Positiiviset ry has previously examined the quality of life of people living with HIV in Finland using a comparable questionnaire in 2013 and 2016, as well as in 2017, when the 15D-survey was also utilized. Based on the quality of life surveys conducted in 2013 and 2016, respondents who were members of Positiiviset ry or had participated in peer activities perceived their lives more positively than others. They reported that HIV had brought more positive aspects to their lives, and they were less affected by the attitudes of others. They also found it easier to find a partner. In addition, they did not feel inferior to others, experience as much loneliness, shame, and guilt, or feel as dirty due to HIV as other respondents. (Positiiviset 2014 & Positiiviset 2017.)

According to the quality of life survey conducted in 2017, half of the respondents had experienced discrimination or inappropriate treatment due to their HIV infection within the last five years. The respondents also indicated that they had disclosed their HIV status to healthcare providers other than those involved in HIV care in 44% of cases. Nearly one-fourth of the respondents (22%) had not disclosed their HIV status to anyone other than those involved in HIV care. Only about 15 % had disclosed their HIV status to their employers. (Positiiviset 2014 & Positiiviset 2017.)

In collaboration with European organisations, the European Centre for Disease Prevention and Control (ECDC) conducted a survey on stigma and discrimination between 2021 and 2022, in which Positiiviset ry was also involved. Responses were collected between November 2021 and January 2022 from a total of 3,272 respondents from 54 European countries. The preliminary results of this pan-European survey indicate that people living with HIV in Europe have experienced stigma in recent years as likely as a decade ago. (Positiiviset 2022, ECDC 2023.)

Conducting the People Living with HIV Stigma Index study is an important milestone, as there is relatively little research-based information in Finland about the stigma and discrimination experienced by people living with HIV. The results can be expected to reduce stigma, as they can be used to design the core features of training and activities, thereby influencing the realisation of the rights of people living with HIV in society. The publication of the results can, in the best case, support the wellbeing of people living with HIV, encourage them to participate in peer activities, and even help prevent new HIV infections.

## 2 Methodology

### 2.1 Execution of the project

The Stigma Index employs a participatory research approach, meaning that people living with HIV were interviewed by other people living with HIV. Simultaneously, the interview situation often served as a peer-support encounter and resource for the respondents. A total of 16 interviewers were recruited, but not all of them ended up conducting interviews. In the end, 9 interviewers participated in the research project. They were not required to have prior experience with this method or any other research work. Efforts were made to recruit interviewers from different key populations of people living with HIV, such as sex workers. The goal was to have as wide and diverse group of interviewers as possible in order to obtain insights from various perspectives within the HIV community. However, efforts to recruit interviewers from key populations were unsuccessful.

The interviewers were trained on conducting interviews. The training covered theoretical knowledge of the definitions of stigma and discrimination used in the study, as well as practical research skills and ethical matters. As part of the training, the questionnaire was thoroughly reviewed to clarify its content and purpose. Additionally, the form was reviewed in order to anticipate any potential challenges that may arise during the interview. The study contained some very personal questions that could cause discomfort or bring up difficult topics, which is why it was important to prepare for such situations in advance.

The respondents were recruited by Positiiviset ry, and the interviewers also recruited respondents themselves. The research and participation were promoted through Positiiviset's own channels, such as social media and their website. Additionally, information about the study was communicated to HIV treatment units across Finland and to organisations that work with people living with HIV. Throughout the entire project, information cards were distributed at the Helsinki University hospital pharmacy, where those living in Helsinki metropolitan area receive their HIV medicines. A dedicated e-mail inbox was set up to facilitate contact. Respondents were not selected; anyone willing could participate in the interview if they met the study criteria (over 18 years old, able to speak Finnish, Swedish, Russian, or English, provided informed consent, living with HIV and having received an HIV diagnosis over a year ago).

In 2020, a standardised methodology was introduced globally for the implementation of the Stigma Index, which all executors of the Stigma Index study are required to follow in the future. When the new methodology was launched, conducting interviews, and collecting data had already been started in Finland. Therefore, the methodology used in this implementation deviates from the new standardised methodology. However, the latest PLHIV Stigma Index 2.0 questionnaire was used in this implementation.

The internationally created materials were translated into Finnish by the staff of Positiiviset ry. To ensure consistency in the implementation, the questionnaire was not altered, and it was translated into Finnish with the aim to maintain it as uniform as possible with the original English version. In addition to Finnish, English- and Russian-language questionnaires were used.

The questionnaire used in the interviews contained a total of 78 questions. These covered themes related to experiences of stigma and discrimination in social situations and healthcare, HIV treatment, HIV testing, and the respondent's knowledge of patient and human rights. The questions also explored the manifestation of stigma as physical or mental violence and self-stigma. Additionally, the interviews addressed stigma or discrimination experienced for reasons other than HIV, including belonging to sexual and/or gender minorities, drug use, and sex work. The time required for an interview ranged between 40 minutes and a few hours. During the interview, the questionnaire was systematically reviewed, and the interviewer recorded the respondents' responses in the questionnaire.

The data consists of a total of 53 interviews conducted between October 2021 and October 2022. The interviews were primarily conducted at Positiiviset's premises. Due to the restrictions imposed by the COVID-19 pandemic, 6 interviews were conducted remotely using Positiiviset's Zoom or Go to Meeting platforms. Written or oral consent for participation in the study was obtained from each respondent. The questionnaire was filled out using numerical codes to maintain the respondent's anonymity from anyone other than the interviewer. The interviews were coded, and Microsoft Excel was used for analysis.

Twelve individuals, six women and six men, participated in the in-depth interviews. The purpose of the in-depth interviews was to uncover personal experiences and gain deeper insights into the past and present stigma experiences of people living with HIV. The respondents were recruited among respondents who had already been interviewed for the Stigma Index study. The interviews also included individuals who had been living with HIV for an extended period and had experiences dating back to the early years of the HIV epidemic. Consent for participation in the in-depth interviews was also obtained from the participants, either in writing or verbally.

The interviews were mostly perceived as meaningful, and the interviewers also found them empowering. Interviewing respondents familiar to the interviewer was sometimes experienced as challenging, as hearing about intimate matters from familiar persons felt uncomfortable. However, none of the respondents wished to interrupt and/or withdraw from the interview. Some interviewers found conducting the interviews emotionally taxing and chose not to continue as interviewers. Support was available throughout the process if any of the respondents or interviewers felt they needed it. Interviews could also be halted at any point by either party's initiative, but such situations did not occur.

*"The interviews brought up forgotten things from my own journey with HIV. The encounters in the interviews gave a sense of meaningfulness. When looking back together, the unpleasant experiences feel less distressing." (Interviewer)*

*"Listening to familiar individuals share difficult and intimate matters became emotionally exhausting over time. It felt like the roles of interviewer and friend became blurred and mixed too much in the situation." (Interviewer)*

*"I spoke openly during the interview, perhaps even too openly. Afterwards, I felt uncertain about what all was recorded." (Respondent)*

*"The interviews could have been done twice; the first time, a lot was left unsaid – and also unasked." (Interviewer and respondent)*



## 3 Results

### 3.1 Background data of the respondents

A total of 53 people living with HIV of different ages from various parts of Finland were interviewed. At the outset of the Stigma Index, basic background information was collected from the respondents. However, those participating in the in-depth interviews were not asked for similar background information to protect their anonymity and avoid creating comparisons with previous interviews.

- **Gender:** 40% were female, 55% were male, and 5 % non-binary (not identifying as female, male, or transgender).
- **Age distribution:** 19% were aged 30-39, 30% were aged 40-49, 32% were aged 50-59, and 19% were over 60. The median age was 50 years.
- **Education level:** 47% had college-, university of applied sciences- or university education, 30% had vocational education, and 13% had secondary education.
- **Employment status:** 57% were full-time employed, and 25 % were retired. The remaining 18% were entrepreneurs, part-time employees, or unemployed. Five respondents reported being students.
- **Relationships:** 58% were in a romantic or sexual relationship. Among those in a relationship, over half were together with an HIV-negative person. A few respondents were uncertain of their partners' HIV status.
- 31 % of the respondents had 1-3 dependent children in their household.

To participate in the Stigma Index study, it was required to have been diagnosed with HIV for more than a year. Thus, participation immediately after the diagnosis was not possible. The majority (76%) of the respondents had known about their HIV status for over 10 years. Nearly one-fifth (18%) had known about it for 5-10 years, and 6% had known about it for 2-5 years. The median time for knowing about the status was 14 years.

The Stigma Index also inquired about stigma experienced for reasons other than HIV. The results show that 17% of the respondents have used drugs like heroin, cocaine, and/or methamphetamine, by injecting or else regularly at some point in their lives. 11% of the respondents identified themselves as current or former drug users at the time of the interview. Some respondents had engaged in sex work or exchanged sex for money or goods, but no one identified themselves as a sex worker.

9% of the respondents reported having faced challenges in meeting basic needs (e.g., food, shelter, clothing) at some point in the past 12 months.

Furthermore, 7 of the respondents felt belonging or having belonged to at least one of the following groups: ethnic or religious minorities, individuals with disabilities (hearing, visual, or physical impairment), refugees or asylum seekers, migrant workers, or prisoners.

Among the respondents, 83% were members of or had participated or been members of support groups for people living with HIV, networks, or associations in Finland.

### 3.2 Disclosing HIV-status

The respondents were asked in the interviews who knew about their HIV-status, whether their status had been disclosed to someone without their consent, and what the experience of disclosing their HIV status has been like. The spouses and partners of most respondents (84%) were aware of their HIV status and a majority (83 %) said their friends were aware as well. About 61% had disclosed their status to other family members. Around half (48%) of the respondents with children had told their children. 26% of the respondents had revealed their status to a co-worker. Somewhat fewer had told their employer (16%), teacher or principal (15%), schoolmates (14%), or community/religious leaders (14%). 9% of the respondents had disclosed their HIV-status to their neighbours.

*In my close circle of friends, I told my friends that I am living with HIV, and everything went well, but the more distant the friend is, the more one thinks about what and to whom one wants to tell about one's status." (Male)*

*"In the workplace I haven't dared to tell anyone that I'm living with HIV, fearing that the information might leak out. When this had happened in the past, people have disappeared from my life." (Female)*

*"In the beginning of the relationship, I didn't tell anyone that I was living with HIV for four years because my partner hadn't talked about their status either." (Male)*

Nearly a third of the respondents (31%) reported that authorities such as the police, judges, and other law enforcement authorities are aware of their HIV status. Among these respondents, 67% said that the matter had been disclosed to the authorities without their consent.

In addition to this, among those whose HIV status was known to others, the HIV status was disclosed without the consent of the respondents not only to coworkers (36%), friends (23%), but also to family members (20%). By whom this had been done by was not asked in the study. A few respondents also shared that their HIV status had been disclosed to an employer, a teacher/principle, schoolmates or to a community or religious leader without their consent.

In the in-depth interviews, it was revealed that disclosing one's HIV-positive status among gay men has resulted in unpleasant experiences in everyday life, restaurants, and/or social media and dating apps. In these situations, stigma and discrimination have surfaced through inappropriate, demeaning, and threatening comments from unknown individuals.

*"It's somehow easier to say you're on PrEP in dating apps than to say you're living with HIV. And on the other hand, why should you talk about your HIV infection when, with medication, it won't transmit." (Male)*

### 3.2.1 Experiences of disclosing HIV status

In the interviews there were statements relating to experiences of disclosing HIV status. They could be responded to by choosing one of the options "agree," "somewhat agree," and "disagree." It was also possible to leave the question unanswered if the respondent felt it did not apply to them (N/A).

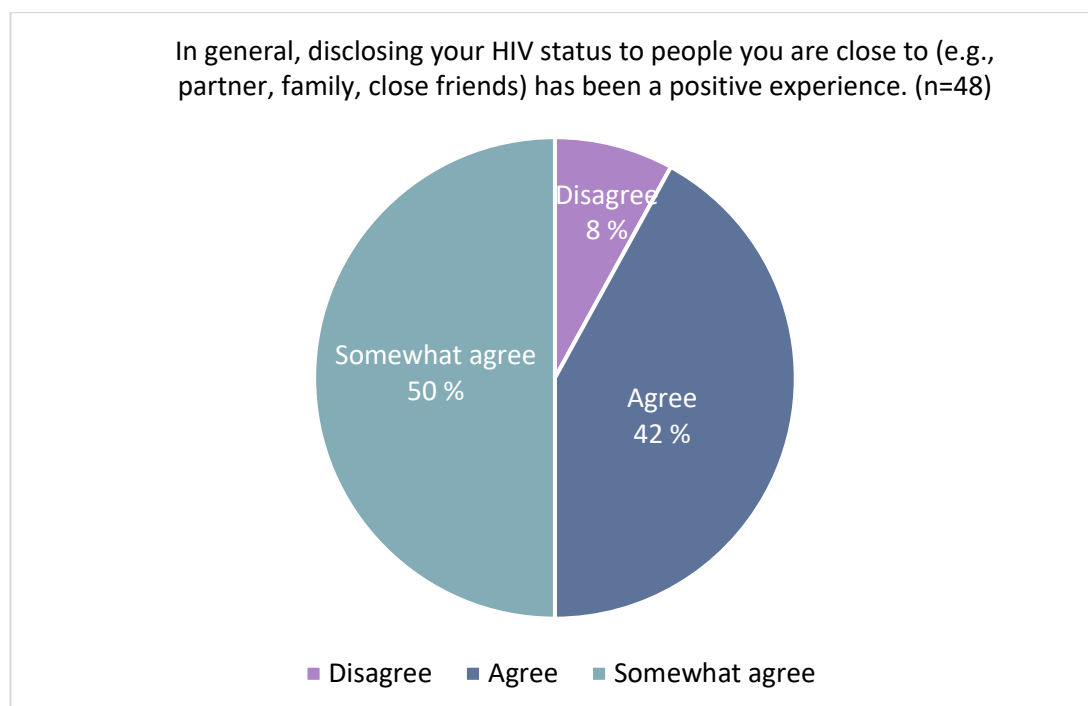


Figure 1: The experience of disclosing HIV status to close persons.

The results indicate that disclosing to close persons has been a positive or rather positive experience for a large portion of the respondents. 42% of them fully agreed and 50% somewhat agreed and 8% disagreed with the statement.

In general, people you are close to were supportive when they first learned about your HIV status. (n=46)

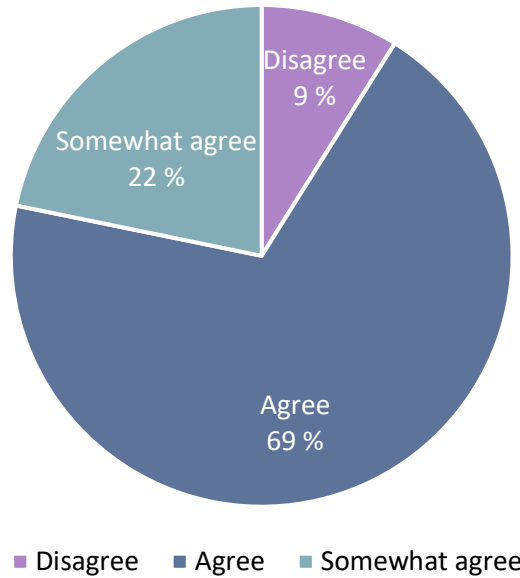


Figure 2: Support from close persons after disclosing HIV status.

70% of the respondents felt they received support from close persons after they had become aware of their HIV status. 22% somewhat agreed with the statement. 9% disagreed, meaning they felt they lacked support from their loved ones after they found out about the respondent was living with HIV.

In general, disclosing your HIV status to people you don't know very well has been a positive experience. (n=40)

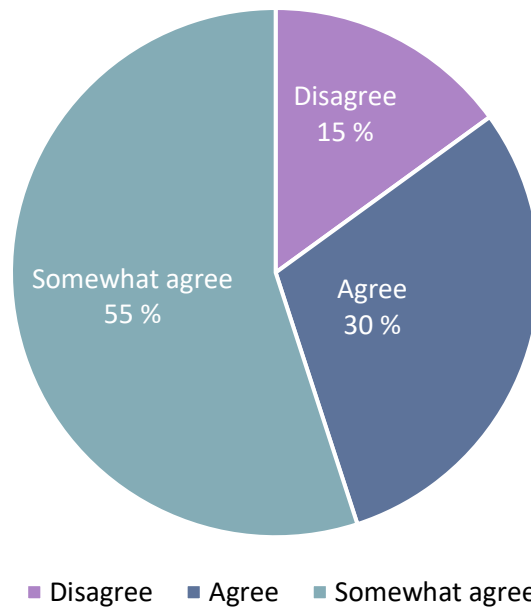


Figure 3: The experience of disclosing HIV status to people not well known.

The respondents were also asked about their experience of telling their HIV status to people they do not know very well. The results indicate that the disclosure has been a positive or somewhat positive experience for most respondents. 30 % fully agreed and 55 % somewhat agreed whereas 15 % disagreed with the statement.

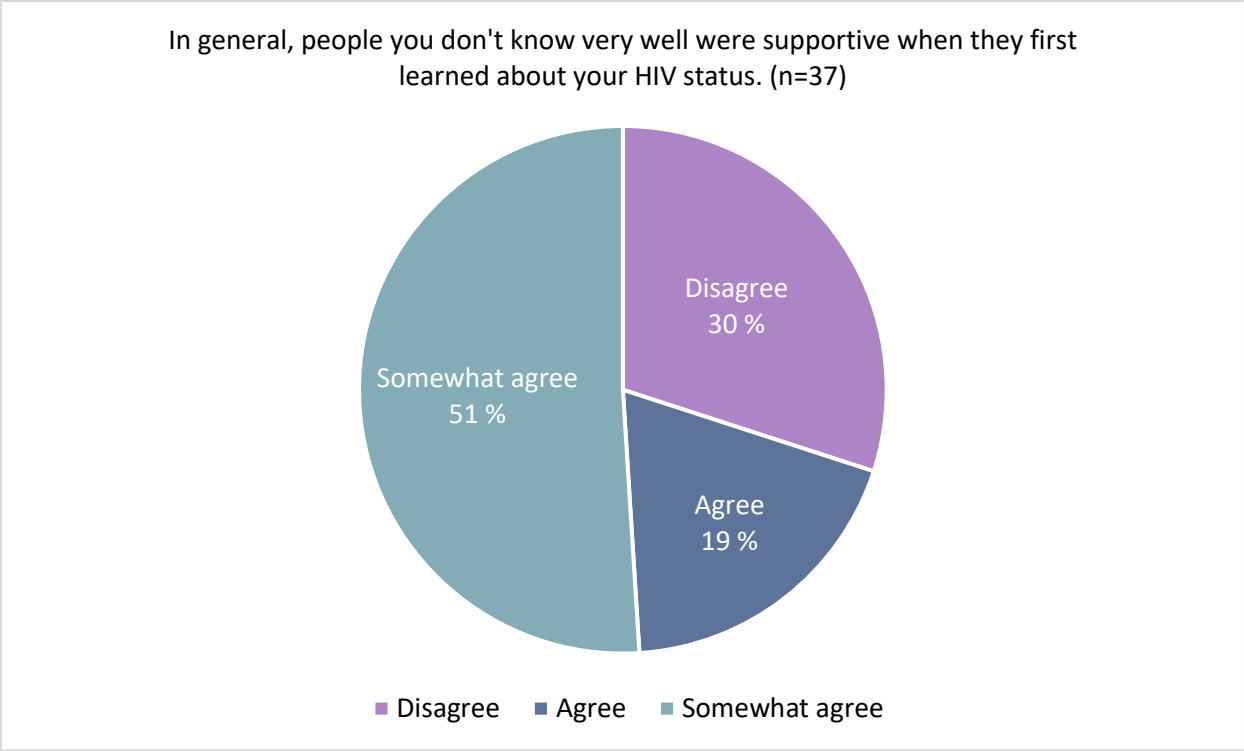


Figure 4: Support received from other people after disclosing HIV status.

19 % felt they received support from people they did not know very well after disclosing their HIV status to them. 51 % somewhat agreed with the statement and 30 % disagreed. The results show that people not so well known to the respondents were slightly less supportive than close persons.

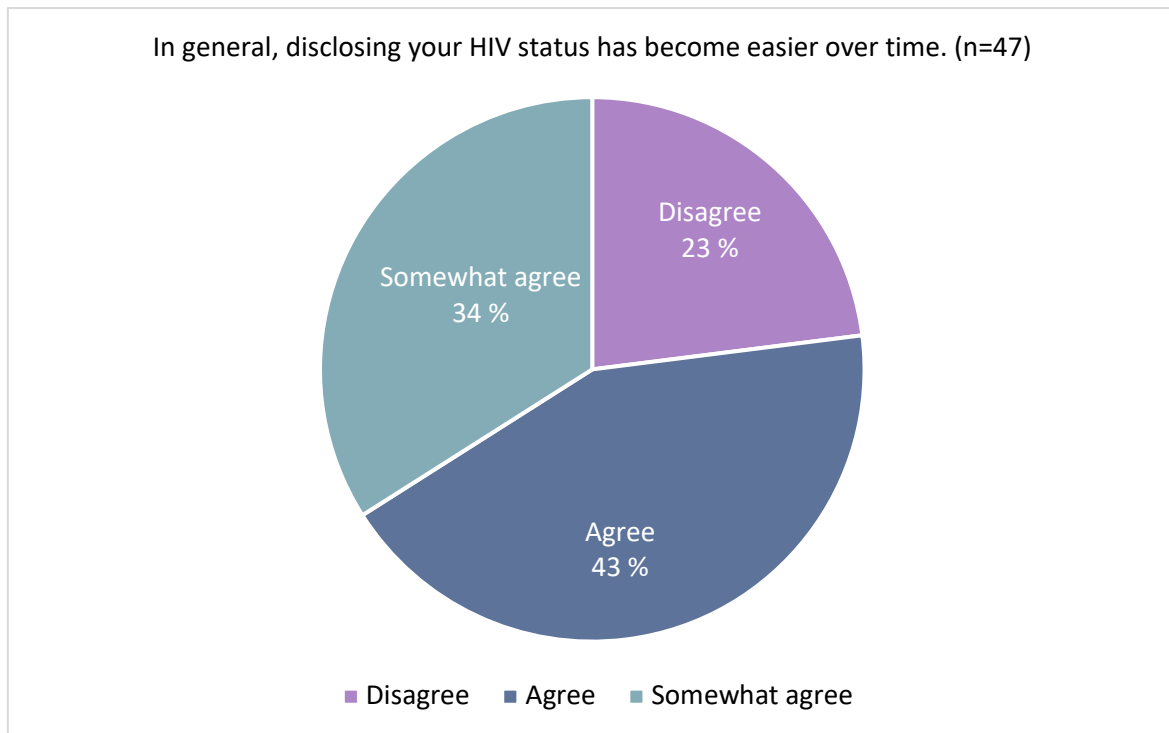


Figure 5: The easing of the HIV status disclosure process over time.

43 % of the respondents felt that disclosing their HIV status had become easier over time. One-third (34 %) somewhat agreed with the statement, and 23 % disagreed. In the in-depth interviews, the ease of disclosure was particularly evident among younger respondents and those who were diagnosed with HIV more recently.

*"When I told my family about my HIV status, my brother already knew about my homosexuality. So, I also received support from him in the situation." (Male)*

*"I no longer tell anyone about my HIV status when there is no need to tell." (Female)*

*"I have told my friends, but I haven't told my small children... stigma affects in the sense that you tell some but not others... On the other hand, HIV stigma affects the situation where even as a parent, your own children already know their mother's HIV status, but cannot talk about it with others. In this way, HIV stigma creates a taboo of silence that goes from generation to generation... It's sad." (Female)*

*"Mentally it has been a big relief to be able to talk openly about living with HIV – the stigma has faded." (Male)*

### 3.3 Experiences of stigma and discrimination

In the interviews, the respondents were asked about the forms of stigma and discrimination they experienced. The questions could be responded either by "yes, within the last 12 months", "yes, but not in the last 12 months", or "no." In addition, it was possible to leave the question unanswered if the respondent felt it did not apply to them (N/A). The results indicate that stigma and discrimination are evident in various ways. The following experiences were more common before, but they were reported also within the last 12 months.

The most experienced form of stigma and discrimination was verbal harassment. It covers yelling, scolding, and other forms of verbal insults. 31% of respondents had experienced verbal harassment, although none in the last 12 months.

Nearly a quarter (24%) of the respondents had ever experienced others than family members gossiping or making discriminatory comments about them due to their HIV-status at some point in their lives. Within the last 12 months, 11% of the respondents had encountered it. One-fifth of the respondents (20%) reported that someone had tried to blackmail them due to their HIV status over 12 months ago. In the last 12 months, 2% of the respondents had had similar experiences.

In the workplace, the stigma and discrimination experienced have not been reported to have occurred during the past 12 months. Over 12 months ago, 13% of the respondents had been denied a job or lost employment or a source of income due to their HIV-status. Furthermore, 9% of the respondents had had changes made to their job duties or were denied a promotion because of their HIV status over 12 months ago.

*"When my workplace found out about my HIV status, I was effectively forced out of my job. Later, I applied for rehabilitation for myself, but I received a response from Kela (the Social Insurance Institution of Finland) stating that I am not eligible for rehabilitation." (Female)*

Some forms of stigma and discrimination had been experienced only by a few respondents in the past 12 months. Despite the small percentages, it is important to recognise the types of stigma and discrimination that exist in society today. Some respondents (2%) were excluded from social gatherings such as weddings, funerals, or other events due to their HIV status. In addition, 14% told this had been the case before the last 12 months. Some respondents (5 %) had found out about a family member gossiping or making discriminatory comments due to the respondent's HIV-status (in addition, 12% reported this happening before the last 12 months). A respondent (2%) had experienced physical harassment or physical hurt, and



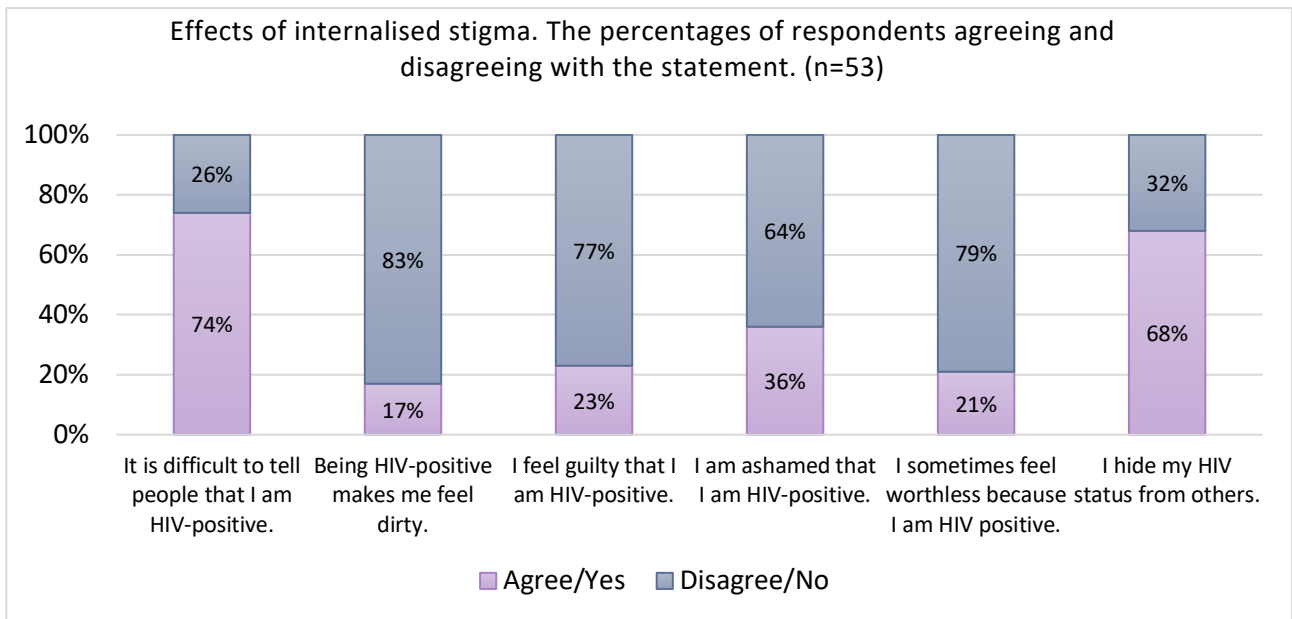
in some (12 %) cases, persons close to the respondent, such as a partner, a spouse, or a child, had faced discrimination due to the respondent's HIV status.

In in-depth interviews, the interviewees said that negative news coverage, especially in the tabloids in the past years, have had a huge impact on their mental well-being. When the media describes transmitting or exposing to HIV, the tone is often stigmatizing and blaming towards people living with HIV. There were particularly violent headlines in the 90s and 80s, but they are still seen today. In the interviews people brought up how stigmatizing it's has been still in last 2-10 years to see headlines about "HIV-murderer or how police is searching for victims of HIV-positive person". Several (3) of the interviewees said that such news headlines have had a permanent impact on them, and that due to the public atmosphere created and preserved by the media, it is difficult disclose one's own HIV status.

It became clear during the in-depth interviews that experiences of stigma and discrimination were influenced by when the respondent had been infected. Those who had been living with HIV for a longer period reported that strong and visible stigma and discrimination were particularly prevalent in the early 1990s. During that time, stigma manifested, for instance, as blatant invasions of privacy and excessive protective measures within healthcare.

### 3.4 Internalised stigma

Stigma is one significant reason why some people have rather negative feelings about themselves because of their HIV-status. Most respondents (74%) mentioned that disclosing their HIV-status to others is difficult. Almost as many (68%) said they hide their HIV status from others. 36% of the respondents feel ashamed of living with HIV, and 21% sometimes feel worthless because of it. 23% of the respondents said they feel guilty and 17% that they feel dirty because of HIV-status.



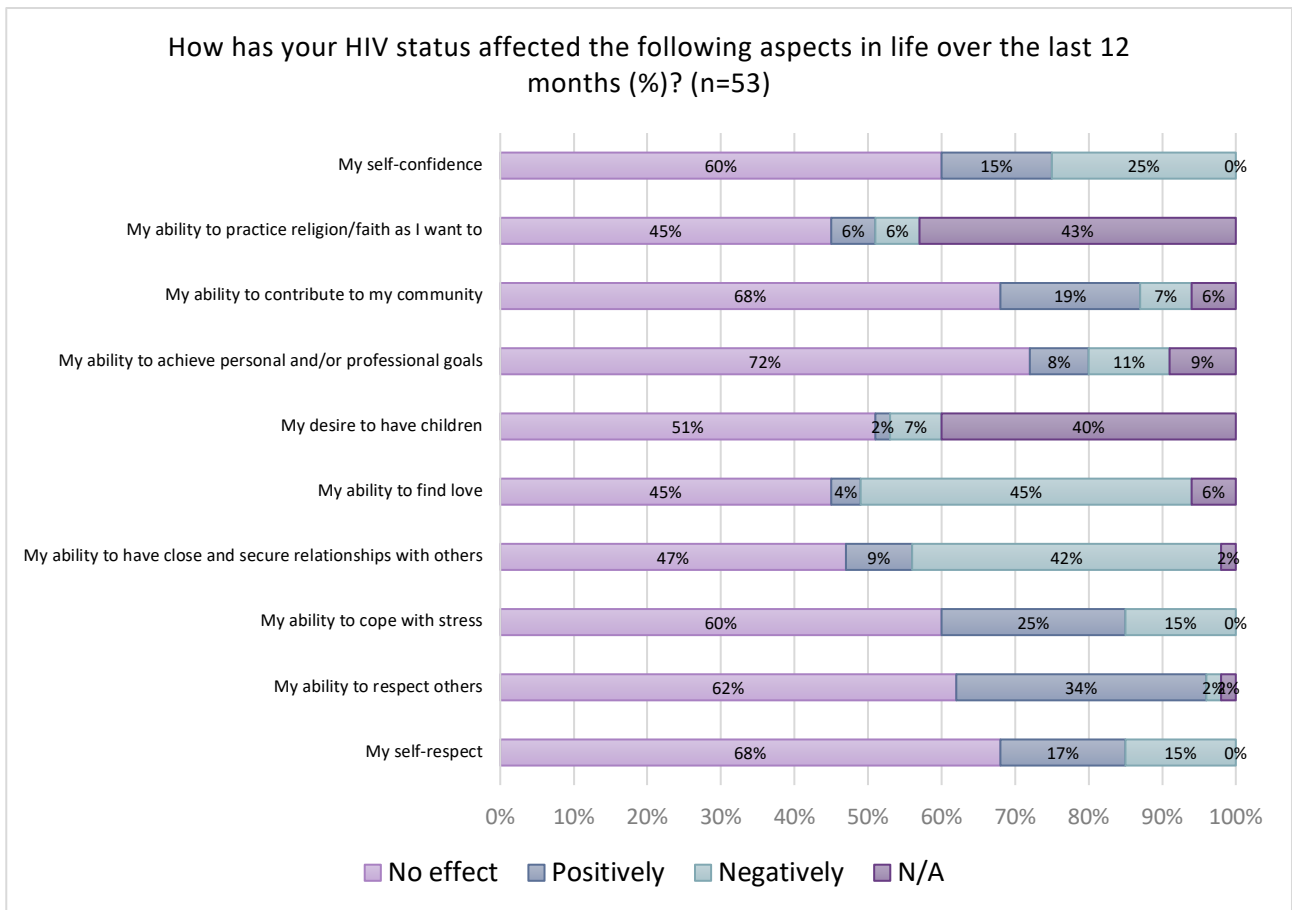
*Figure 6: The impact of internalized stigma.*

The respondents were asked how their HIV status affected different aspects in their lives in the last 12 months. The options were positively affected, negatively affected, not affected, or N/A. The most negative impact of HIV was on the possibility to find love (45%) and the ability to build close and secure relationships with other people (42%). Self-confidence had been negatively affected by HIV in one-fourth of the respondents (25%). However, 15% of the respondents said that the impact on self-confidence had been positive.

HIV had negatively affected self-esteem in 15% of the respondents, and 17% felt that their HIV status had a positive impact on their self-esteem. One-third of the respondents (34%) felt that HIV had a positive effect on their ability to have close and secure relationships with others. A quarter (25%) reported a positive impact of HIV on their ability to cope with stress, whereas 15% said the impact was negative.

19% of the respondents said that HIV had a positive effect on their ability to contribute to their community. Negative impacts in this regard were minimal (7%), but over half of the respondents reported that HIV had no effect on their ability to contribute to their community. Additionally, HIV status had not affected the majority (72%) of the respondents in achieving their personal and professional goals. Nonetheless, 11% of the respondents mentioned a negative impact.

Nearly half (45%) of the respondents said that their HIV status had no effect on their ability to practice their religion as they wished. Around half (51%) of the respondents expressed that their HIV status had no impact on their desire to have children.



*Figure 7: The impact of HIV status on various life aspects in the past 12 months.*

The respondents were also asked to assess whether the situation has changed. The majority (70%) felt that it was almost the same as over a year ago, 21% felt that it was now better than before, and 9% felt that it was worse than before. In the in-depth interviews, it came out that after living with HIV for well over ten or twenty years, one starts to incorporate HIV as part of one’s own life story and can see the positive things in life that HIV has brought along.

The respondents were asked how their HIV status has affected their behaviour or choices. In the past 12 months, 18% of the respondents made the choice not to engage in sex, 11% chose not to seek healthcare, 10% not to attend social gatherings, 8% not to apply for a job, another 8% chose to isolate themselves from family and/or friends, and 2% chose not to seek social support because of their HIV-status.

*“Stigma is always given and comes from the outside, no one just invents it in their minds. Therefore, the responsibility for stigma and discrimination always lies within the structures of society.” (Female)*

*"You have to consider things within your circle of friends when you disclose your HIV-positive status, and you receive unpleasant comments." (Male)*

*"Not being able to disclose their HIV status or feeling the need to conceal it creates a continuous stigma from generation to generation, that lives on through secrecy." (Female)*

### 3.5 Interactions with healthcare services

Most respondents (83%) had independently sought an HIV test at some point on their own initiative. Some respondents (6%) had decided to take the test but were pressured by others to do so. For a few (11%), the test was done without their consent or knowledge. That means that they found out about it when receiving a positive test result. None of the respondents had been forced to take the test without consent, and no one had been living with HIV since birth.

Those who intentionally took the HIV test were asked about the reasons behind their decision. Nearly half of the respondents (45%) sought the test because they believed they had been in a situation where HIV transmission was possible. Some had also sought the test based on healthcare recommendation (17%) or simply because they wanted to know their HIV status (17%). For some, the decision to get tested was prompted by an illness and their own or their family's concern that it might be related to HIV (11%).

A majority of those who took the test on own initiative (70%) had done so within six months of becoming aware of the need for it. For 17% of the respondents, it took more than 6 months and up to 2 years from the initial awareness of the need of a test to getting tested. In no case had it taken more than two years, although some respondents (13%) could not remember how long it had been. 17% of those who intentionally sought the test mentioned that the fear of how others (such as friends, family, or employers) would react to a positive test result made them hesitate to take the test.

In the Stigma Index interviews, the respondents were asked if there was any reason that made them hesitate or delay starting with HIV medication. All respondents had experienced some hesitation or delay in starting medication. For 23% of the respondents, the concern that starting with HIV medication would reveal their HIV status to others influenced their decision. Slightly fewer (21%) mentioned that they hesitated with or delayed the medication because they were not ready to deal with their HIV infection. Nearly as many (19%) feared that healthcare staff would treat them poorly or disclose their HIV status without their consent. A slightly smaller number cited concerns about their partner, family, or friends finding out about their HIV status (9%), or previous negative experiences with healthcare (11%).

Currently, HIV medication is recommended to be initiated immediately or as soon as possible after HIV diagnosis. In the past, starting treatment was delayed, and HIV medication was recommended only when the person's health deteriorated or the CD4 cell count was low. Most respondents (83%) stated that they had decided to start with the medication as soon as it was offered to them. 11% of the respondents decided to wait and started with the treatment later. 6% of the respondents reported that some other reasons influenced their decision, such as mental health-related challenges. None of the respondents felt that a healthcare representative had pressured them to start HIV treatment.

All the respondents reported that within the last 12 months it had been confirmed to them that their viral load was undetectable.

### 3.5.1 Non-HIV related healthcare

Nearly every respondent (96 %) had experiences with healthcare unrelated to HIV in the last 12 months. Over half of the respondents (60 %) reported that they usually disclose their positive HIV status when seeking healthcare unrelated to HIV.

The respondents who had sought healthcare for reasons unrelated to HIV (n=51) were asked about how they were treated in those situations in the last 12 months. None of the respondents had experienced mistreatment such as yelling, rebuking, or insulting, or physical violence. Some individual experiences came up where healthcare providers had spoken in an unpleasant tone or gossiped because of the respondent's HIV status (6%), and where the respondent's HIV status had been disclosed to others without consent (6 %). Experiences of being refused treatment due to the HIV status were particularly reported in dental care (8%). In other healthcare settings, these experiences were nearly non-existent (2%). Cases of healthcare staff trying to avoid touching the respondent or taking extra precautions with them (such as excessive use of protective gear) were reported by 16% of the respondents.

*"Well, I can't really say that I encounter stigma in healthcare because I never even tell that I am living with HIV. And that, too, is because of the stigma." (Female)*

Particularly in the in-depth interviews, it became evident that almost all women living with HIV have experienced discrimination and prejudice during pregnancy and at delivery as well as in choosing a contraceptive method. The reported experiences were from over a year ago: women living with HIV had been advised to terminate pregnancies (4) or pressured into choosing a specific contraceptive method (5)

without discussing other options. Additionally, respondents had been pressured into a particular method of giving birth (6). Respondents had been pressured into a specific method of infant feeding (6).

*"After giving birth, I was simply informed that I shall not breastfeed my baby so that I won't transmit the virus. The way I was addressed was unpleasant, and I felt like as a new mother living with HIV, I wasn't trusted." (Female)*

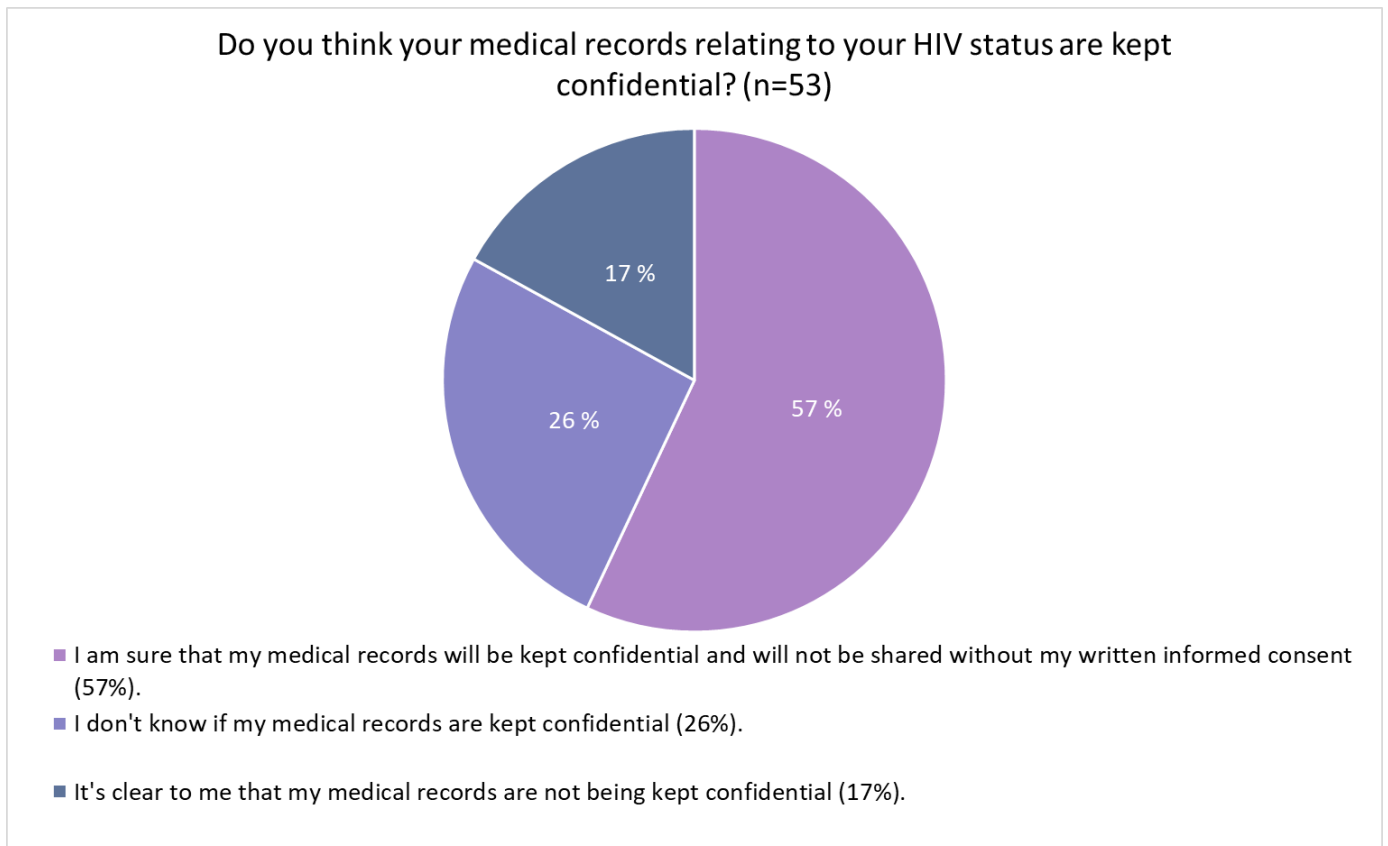


Figure 8: Trust in medical confidentiality.

The respondents were also asked to assess their trust in the confidentiality of their medical records. 57% of the respondents were convinced that their medical records related to HIV remain confidential. Conversely, 17% were convinced that they would not be kept confidential. One-fourth (26%) responded that they do not know if the records are kept confidential.

### 3.5.2 Experiences of HIV treatment

*"In 2008, my doctor pitifully expressed his condolences after having informed me of the HIV infection." (Male)*

All the respondents were on HIV medication at the time of the interview. 17% of the respondents had temporarily interrupted their HIV medication at some point but later resumed it. Reasons for the interruption included, for example, pregnancy or the unsuitability of the medicine. A few respondents (4%) said that sometime during the last 12 months fear of their HIV status being revealed had led them to skip a dose of their medication.

All the respondents receive HIV treatment through public healthcare services. In Finland, HIV is treated in specialised healthcare, either at central hospitals or university hospitals' infectious diseases clinics, depending on the place of residence.

Most (73%) respondents reported being in good health at the time of the interview. 18% reported feeling moderately well, and 9% perceived their general health as poor.

Experiences of discrimination in HIV-related healthcare were rare, but even the occurrence of minor incidents indicates the existence of stigma. Isolated incidents of discrimination in HIV-related healthcare in the last 12 months were reported in the following situations.

- *I have been refused treatment because of my HIV status (2%).*
- *I have been advised not to engage in sex because of my HIV status (2%).*
- *I have been talked badly about or gossiped about because of my HIV status (4%).*
- *They have tried to avoid physical contact or taken extra precautions because of my HIV status, e.g., healthcare staff overly protecting themselves (8%).*
- *My HIV status has been disclosed to other people without my consent (2%).*

Based on the in-depth interviews, people living with HIV have experienced discrimination and stigmatisation outside of HIV care or infectious disease clinics, particularly in various healthcare facilities. Stigma and discrimination have been encountered in health centres in different cities and towns, laboratories, dental clinics, gynaecological outpatient clinics, maternity wards, maternity clinics, and social services (e.g., child protection services) in Finland. The interviews revealed that there are still prejudices and lack of knowledge about HIV and HIV medication among the healthcare staff, as well as fear of HIV transmission.

*"In 2022, after booking me a doctor's appointment at the health centre, a nurse told me that I should make sure that I won't infect the doctor in the consulting room." (Female)*

In previous years and even in 2022, some of the respondents have heard from healthcare personnel in customer service that as a person living with HIV, they were feared to infect the healthcare staff in the facilities. Such situations have occurred, for example, at a health centre and gynaecological outpatient clinic. Some of the respondents had to inform the healthcare staff about HIV and explain that with proper treatment HIV will not transmit.

*"It is hard being an HIV ambassador." (Female)*

The in-depth interviews revealed particularly blatant discrimination that occurred in the public dental care in the Helsinki metropolitan area during the years 2007-2010. Stigma and discrimination have manifested as denial of treatment based on HIV status and/or serious misconduct in dental care, especially among people living with HIV that belong to marginalised groups, such as people who use drugs.

*"In 2010 I was told at the dental clinic that there is no use in treating me because I am living with HIV." (Male)*

In the in-depth interviews it came up that HIV registered in the medical records has caused concern and stress among the respondents. The respondents have noticed that living with HIV evokes fear and prejudice among healthcare staff. This has led to inappropriate measures in some circumstances, such as excessive use of multiple layers of rubber gloves for protection. A laboratory nurse had also expressed fear of being infected in front of the patient.

The interviews also brought to light that the notation of HIV in the medical records has led healthcare personnel to assume that the individual is a person who uses/injects drugs. The impact of stigma has also been evident in doctors' treatment plans, which were derived from assumptions of poor life management and inability to take care of aspects like oral hygiene because of HIV status. Similar experiences of assumed poor life management have been reported in maternity clinics, delivery units, social services, and student health care.

*"After my child was born, I was in the hospital treatment room, and during a doctor's visit, the doctor asked me if I had any other life management-related issues [besides HIV]?"  
(Female)*

In the in-depth interviews, some of the respondents said they had turned to private healthcare due to poor or inappropriate experiences in public healthcare, and to prevent their HIV status from being recorded in



records visible across all healthcare units. In these cases, information about HIV infection was not disclosed when seeking private services.

In the in-depth interviews, concerns about privacy were also raised regarding other government or healthcare services. Some respondents had experienced severe breaches of privacy as a person living with HIV during the early days of the HIV epidemic and even in the 1990s. Some of these breaches of privacy led to legal actions.

On the contrary, the respondents also shared experiences of positive and appropriate encounters both in public and in private healthcare. Furthermore, the in-depth interviews highlighted how some respondents had recovered from the AIDS stage and serious illnesses after starting medication and how remarkable this had been. In these stories of recovery, an immense gratitude was expressed to the healthcare staff for providing humane care.

## 4 Discussions

The Stigma Index project was aimed to collect information about the stigma and discrimination experienced by people living with HIV in different life situations. The goal was to highlight societal norms and structures that affect the quality of life and wellbeing of people living with HIV in Finland. Additionally, the objective was to gather information that can be used in advocating for and promoting the fundamental and human rights of people living with HIV.

Today, HIV treatment allows for a normal lifespan. People living with HIV can lead fulfilling lives without fear of the health effects caused by HIV. Moreover, treated HIV does not transmit to others. However, the Stigma Index study shows that significant stigma associated with HIV and the resulting experiences of shame and exclusion are still present in the daily lives of people living with HIV. These experiences can impact their everyday life choices and limit opportunities to live life as they wish. The study reveals that within the last 12 months, 18% of the respondents made the choice to abstain from sex because of HIV, 11% chose not to seek healthcare, 10% not to participate in a social event, 8% not to apply for a job and 8% chose to isolate themselves from their families and/or friends due to their HIV status. These are alarming signs of the impact of HIV-related stigma on individuals.

The results of the Stigma Index study demonstrate that stigma is a part of everyday experiences and encounters of people living with HIV. The most experienced form of stigma within the last 12 months was internalised stigma, which is a continuation of the prevailing attitudes and prejudices in society. Among the respondents, 36% reported feeling ashamed, 21% sometimes felt worthless, 23% guilty, and 17% dirty for living with HIV.

Many people struggle with when and to whom to disclose their positive HIV status. Some people living with HIV may choose not to tell anyone. According to the Stigma Index results, for some people living with HIV revealing one's HIV status is easier today than for some years ago. Disclosing their HIV status had become easier over time for 43% of the respondents. However, it is still not easy. Only about half (50%) of the respondents found disclosing their HIV status to close persons to be a positive experience. Nonetheless, the majority (70%) felt supported by their loved ones when sharing the matter with them. It is important to note that many of the respondents had been taking part in Positiiviset's peer support activities for a long time. For example, people who have never disclosed their HIV status to anyone except healthcare personnel were not reached by this study. In an online quality of life survey conducted in 2017 by Positiiviset, 22% of

the respondents had not disclosed their HIV infection to anyone except the healthcare service providers that they received treatment from (Positiviset 2017).

The Stigma Index study shows that experiences of stigma and discrimination were more common in the past than they are today. In the in-depth interviews, people who had lived with HIV for a longer time reported stigma and discrimination being pervasive and prominent, particularly in the 1980s and 1990s. Back then, stigma manifested itself through invasions of privacy and excessive protective measures in healthcare. However, the in-depth interviews also showed that the recentness of stigma experiences does not immediately reflect their impact. Even if the negative experiences are not from the past year, stigma, discrimination, and prejudiced comments can continue to affect people's lives for a long time. It is evident that years of unpleasant experiences have left strong marks on people living with HIV. Individuals have started to modify their behaviour to avoid situations where they have experienced external stigma. For instance, 68 % of the respondents of the Stigma Index study reported hiding their HIV status from others.

The results of the Stigma Index make it evident that although a humane social and healthcare system is everyone's right, HIV-related stigma still exists within healthcare. Seeking healthcare can cause concern and stress for people living with HIV who have had prior experiences of being treated inappropriately. People living with HIV have encountered disrespectful treatment and healthcare professionals have displayed negativity and lack of knowledge about HIV even in recent years. Experiences like avoidance of physical contact or being the object of excessive protective measures were reported by 16% of the respondents. People living with HIV also require medical treatment throughout their lives for reasons other than HIV-related ones. It is unsustainable that perceived stigma keeps people living with HIV from seeking healthcare or that the fear of disclosing their HIV status prevents them from trusting healthcare personnel. Everyone should be able to turn to healthcare without fear of being discriminated against or treated disrespectfully.

By 2023, over 500 HIV-negative babies have been born to mothers living with HIV in Finland. According to the World Health Organization (WHO) recommendations, mothers living with HIV can breastfeed when they receive HIV medication and treatment, and their viral load is below the threshold (WHO 2016). In Finland, as of the summer of 2023, the practice is not to recommend breastfeeding but no longer categorically forbid it. If a mother living with HIV in Finland decides to breastfeed, it is hoped she will inform the healthcare unit so that the situation can be monitored, and necessary support can be provided.

The ongoing HIV-related stigma is rooted in the prejudices, attitudes, and fears of people, as well as in societal structures that uphold stigma. The stigma that is present in and supported by power structures poses a critical obstacle to the normalisation of HIV. Stigmatising comments can be paralyzing and can be

difficult to respond to immediately. They may push individuals deeper into the "closet" or cause internal grief. Structural stigma can also be invisible and can be perpetuated both consciously and subconsciously.

Breaking the stigma related to HIV cannot be the sole responsibility of people living with HIV. Speaking openly about one's HIV diagnosis is an example of how HIV and HIV-status can be normalised, both within one's immediate circle, in society and in public discourse. However, publicly disclosing one's diagnosis can be stressful. In some situations, it can also lead to feelings of insecurity. What is needed is the strength of and allyship within communities to dismantle prejudices and spread awareness about HIV and living with HIV. Addressing structural stigma requires its recognition at the societal level.

Conducting the Stigma Index study in Finland has, for the first time, enabled the measurement of the stigma and discrimination experienced by people living with HIV in Finland and a broader examination of the phenomenon. Furthermore, the results obtained from the project will help advocate for and promote the rights of people living with HIV, such as equality in services. Based on the results, it is possible to formulate recommendations for action that can enhance the equality of people living with HIV in Finland. These recommendations can also help identify aspects that perpetuate stigma in societal structures that have not been previously recognised or questioned. Thanks to this study, we can better discern the covert nature of stigma and how to work towards defeating it in the future.

#### 4.1 Results and recommendations

Based on the results of the Stigma Index study a list was drawn of recommended measures to improve the situation in Finland. Concrete measures for improving the situation will be specified in Positiviset's advocacy work.

- **In Finland, treatment guidelines and work culture should be developed where people living with HIV and particularly those belonging to marginalised groups, are met with equality and dignity.**

Through treatment guidelines and work culture among healthcare professionals, HIV-related stigma, discrimination, and privacy violations in healthcare can be reduced.

- **The privacy and confidentiality of people living with HIV must be improved at all levels of society and communities.**

It is to be ensured that people living with HIV are aware of how their HIV status appears in their health records. It is essential to know who has access to the information. When developing work culture among healthcare professionals, it is necessary to consider, for example, in what situations HIV may or may not be discussed out loud, such as in hospital hallways.

- **Accurate and up-to-date information about HIV, its transmission, and living with HIV should be shared across various levels of society.**

Education and information should be provided in schools, communities, healthcare organisations and workplaces. Accurate information can reduce fear, prejudice, and misunderstandings.

- **People should be encouraged to challenge HIV-related stereotypes and prejudices.**

Eliminating HIV-related stigma cannot be solely the responsibility of people living with HIV; it requires comprehensive action and allyship from the entire society.

- **Use of appropriate terminology and vocabulary**

It's essential to use language that doesn't increase and exacerbate stigma. This also applies to social and health care services. The media has a responsibility to report and inform about HIV in a timely manner. Highlighting HIV in the media only in the context of negative events or in relation to certain groups of people increases stigma and sustains prejudice.

- **Safe spaces and peer support groups for people living with HIV should be created and maintained.**

Peer support is important for people living with HIV to share experiences, receive support, and build a community. Such communities can help reduce stigma and provide resources for people living with HIV.

- **The realisation of social justice should be promoted.**

Promoting social justice and protecting human rights are essential in reducing HIV stigma. The dignity of every individual should be recognised, and action taken to promote such thinking.

- **Inequality and discrimination should be reduced at all levels of society.**

HIV stigma can lead to discrimination, poverty, gender inequality, and other social injustices. People living with HIV and those at a specific risk to be infected with HIV often belong to other stigmatised groups. Various forms of discrimination and stigma need to be addressed.

- **Peer support is the most efficient way to reduce internalized stigma.**

Those who participate in peer support apply for and receive different things from it. For some, the central importance of peer support is the sharing of personal experience. It has been thought that peer support can empower, integrate and can be experienced as liberating.

Reducing stigma is a long-term process that requires continuous effort and commitment. Measures and programs must be sustainable and regularly monitored and evaluated. The work must be ongoing and

dedicated. A comprehensive and holistic approach is a key factor in the fight against stigma. A multi-level approach and collaboration at all levels, including policymakers, healthcare professionals, non-governmental organisations, schools, and communities, are needed to defeat stigma.

HIV medication maintains the health of a person living with HIV, and treated HIV does not transmit. Although people living with HIV can now live their lives on their own terms, peer support and sharing common experiences is still important. The publication of study results such as the Stigma Index can, in the best case, support the wellbeing of people living with HIV, encourage their participation in peer activities, and through increased knowledge, contribute to the prevention of new HIV infections.

As the results of the Stigma Index and the narratives of the respondents reveal experiences of stigma and discrimination vary over time and in different situations and environments, but they are always present in one way or another. Stigma can be experienced within one's inner circle, in healthcare settings, as well as more broadly within society and public systems. It is crucial to identify the various forms of stigma in different cases to address and reduce it. Bringing forth experiences of stigma and discrimination is the only way to help address the issue, as appropriate action is impossible without knowledge. The Stigma Index project has encouraged people to share their experiences. It is desirable that the publication of the study results and the ensuing discussion would encourage more individuals to articulate their experiences with less hesitation.

## 4.2 Limitations of the study

The most significant limitation of the study was the COVID-19 pandemic, which began in Finland in March 2020. The pandemic and the associated restrictions interrupted the first phase of the Stigma Index interviews in Finland, and in 2021, the process had to be partially restarted. However, challenges in recruiting respondents continued in the post-COVID-period. This was particularly the case with respondents who were not connected with the peer community or other people living with HIV. Infectious disease clinics are an essential means of reaching people living with HIV, and flyers for the Stigma Index study were distributed there. During the COVID-19 pandemic, visits to the clinics were limited, making communication, and reaching people very challenging.

Furthermore, the state of emergency caused by the pandemic poses a limitation on the generalisability of the study results. The research interviews were conducted in 2021 and 2022, which means that the interview period and its preceding 12 months were somewhat exceptional times. It is evident that the

exceptional global situation has had an impact on people's lives, which may also be reflected in the responses and in the results of the study.

The Stigma Index questionnaire also included questions about the realisation of human rights in Finland and experiences of non-HIV related stigma and discrimination. These include belonging to a sexual and/or gender minority, drug use, and sex work. With 53 respondents, the sample size of the Finnish Stigma Index study was small, and very few responses concerning those areas were received. Due to the small number of responses, these sections and questions have not been analysed in this report. The human rights situation in Finland is good, and the respondents did not report exceptional violations or restrictions. Besides, reporting and analysing responses of a sample of only a few persons belonging to different key populations would not have been ethical. For the same reason, gender differences are not reported in this report. It is clear that women have more experiences related to sexual and reproductive health and rights, which have been associated with a lot of stigma, discrimination, and inappropriate treatment.

In the future, and particularly in conjunction with the possible repetition of the Stigma Index study, it would be essential to include more individuals belonging to different key populations to be able to describe the phenomenon more broadly and accurately. In addition, in this study, most respondents were born in Finland, so in the future, it would be important to gather experiences from immigrants as well.

## References

- Babel RA, Wang P, Alessi EJ, Raymond HF, Wei C. (2021) *Stigma, HIV Risk, and Access to HIV Prevention and Treatment Services Among Men Who have Sex with Men (MSM) in the United States: A Scoping Review*. *AIDS Behav.* 2021 Nov;25(11):3574-3604.
- ECDC (2023). European Centre for Disease Prevention and Control. *Stigma: survey of people living with HIV. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2022 progress report*. Stockholm: ECDC; 2023.
- GNP+ (2023). *About the Stigma Index*. Retrieved on 17 May 2023 from <https://www.stigmaindex.org/about-the-stigma-index/>
- Huotari, K (1999). *Positiivista elämää: HIV-tartunnan saaneiden selviytyminen arjessa*. Helsingin yliopisto.
- KKO (2021). *Precedential decision by the Supreme Court of Finland 2021:64*. Helsinki 2021.
- Nikkanen H & Järvi A (2014). *Karanteeni: kuinka aids saapui Suomeen*. Kustannusosakeyhtiö Siltala.
- Nobre, N (2018). *Quality of life of people living with HIV/AIDS in Finland*. University of Helsinki. <http://urn.fi/URN:ISBN:978-951-51-4488-1>
- Positiiviset ry (2014). *Elämänlaatukselyn tulokset (Results of the quality of life -survey)*. *Poveri (magazine)* 4/2014, 6–25.
- Positiiviset ry (2017). *Elämänlaatukselyn tulokset (Results of the quality of life -survey)*. *Poveri (magazine)* 2/2017, 6–29.
- Positiiviset ry (2022). *Väittämiä stigmasta (Statements about stigma)*. Helsinki 2022.
- THL (2017). *Suomen hiv-strategia 2018–2020: Ehkäise, testaa, hoida*. OHJAUS 28/2017. Juvenes Print – Suomen Yliopistopaino Oy. Helsinki, 2017. <https://urn.fi/URN:ISBN:978-952-302-983-5>
- THL (2022). HIV-rekisteri. Retrieved on 17 May 2023 from <https://repo.thl.fi/sites/laaturekisterit/hiv-rekisteri/>
- THL (2023a). *Hiv ja aids esiintyvyys ja tilastot (HIV and AIDS prevalence and statistics)*. Retrieved on 17 May 2023 from <https://thl.fi/aiheet/infektiotaudit-ja-rokotukset/taudit-ja-torjunta/taudit-ja-taudinaiheuttajat-a-o/hiv/hivin-ja-aidsin-esiintyvyys>
- THL (2023b) *Stigma ja syrjintä*. Retrieved on 17 May 2023 from <https://thl.fi/aiheet/mielenterveys/mielenterveyden-edistaminen/stigma-ja-syrjinta>
- Turan B, Budhwani H, Fazeli PL, Browning WR, Raper JL, Mugavero MJ, Turan JM. (2017) *How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes*. *AIDS Behav.* 2017 Jan;21(1):283–291.
- UNAIDS (2022). *A framework for understanding and addressing HIV-related inequalities*. Retrieved on 17 May 2023 from <https://www.unaids.org/en/resources/documents/2022/framework-understanding-addressing-hiv-related-inequalities>
- WHO (2016). World Health Organization, United Nations Children’s Fund. *Guideline: updates on HIV and infant feeding: the duration of breastfeeding, and support from health services to improve feeding practices among mothers living with HIV*. Geneva. World Health Organization 2016.
- Yhdenvertaisuuslaki (The Finnish Non-Discrimination Act) 30.12.2014/1325.