

# Unknown Lives

: Initial Findings

*From The People Living with*

*HIV Stigma Index In South Korea 2016-2017*



The People Living with HIV Stigma Index was developed by these three organizations:

- The Joint United Nations Programme on HIV/AIDS (UNAIDS)
- The Global Network of People Living with HIV/AIDS (GNP+)
- The International Community of Women Living with HIV/AIDS (ICW)

The Korean Network for People Living with HIV/AIDS (KNP+) coordinated the South Korean rollout of The People Living with HIV Stigma Index. The organizing team includes:

- Solidarity for HIV/AIDS Human Rights, Nanuri+ (<http://www.aidsmove.net>)
- The Korean Youth HIV/AIDS Community, AI
- The Korean Gay Men's Human Rights Group, Chingusai (<https://chingusai.net>)
- The Solidarity for LGBT Human Rights of Korea (<http://www.lgbtpride.or.kr>)

This research becomes possible because of 15 motivated field researchers who conducted 104 survey interviews and 15 in-depth interviews. Hanrim University provided technical assistance for ensuring ethical protocols for this research. Sincere thanks go to all the people who took the time for the interviews to be part of this important worldwide initiative. The Korean People Living with HIV Stigma Index team also thanks the UNAIDS Regional Support Team for Asia and the Pacific and 42 individual sponsors who made donations through Social Punch.



# Introduction

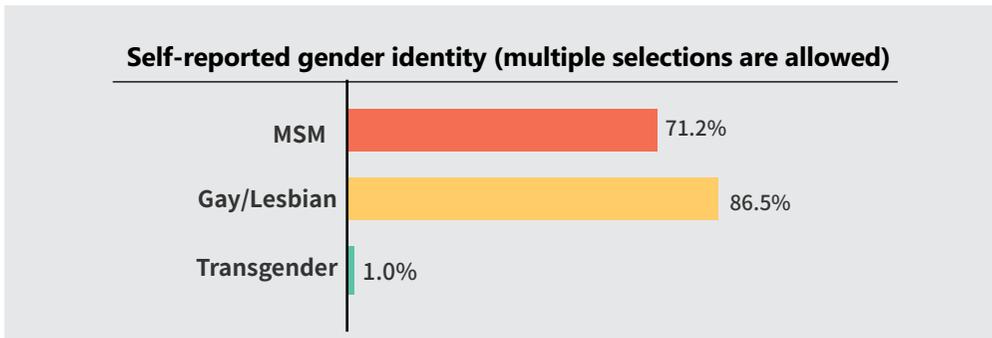
From March 2016 to June 2016, 15 field researchers met 104 people living with HIV in South Korea and asked about their experiences of stigma and discrimination in the last 12 months. The survey was conducted through a translated version of the standardized questionnaire developed by the UNAIDS and associated institutions. In this brochure we present selected results from the statistical analysis broken down into the following sections:

1. Social Demographic of Respondents
2. Experiences in Healthcare
3. Work and Employment
4. Sexuality and Reproduction
5. Openness about HIV Status
6. Internalization of Stigma
7. Rights and Social Environment
8. Effecting Changes

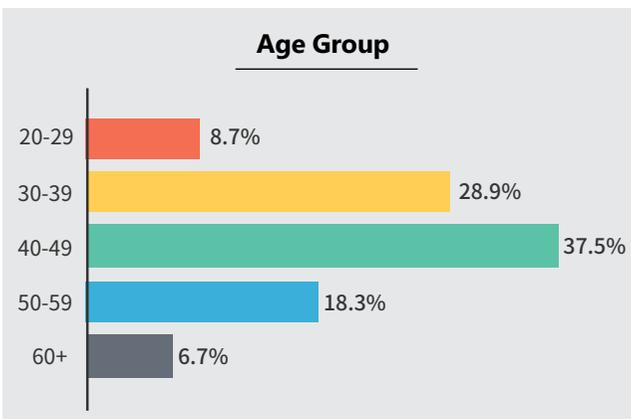
In addition to questionnaire-based survey, 15 in-depth interviews were also conducted to learn more about the everyday lives of people living with HIV in South Korea. The full analysis including qualitative data is available from the full report in Korean.

# 1. Social Demographic of Respondents

98% of survey respondents are men, 1% are women, and 1% are transgender people.



90 respondents checked the category “gay and lesbian,” and it means that the most of respondents are gay male. 74 respondents answered that they are “MSM (men who have sex with men)”. The number of respondents who checked the MSM category is smaller than who identified themselves as gay, because MSM category is interpreted in this context as something indicates that they are sexually active.



In terms of age, 30-49 year olds form the biggest proportion of respondents with 66%, followed by those over 50 (24%), and those under 29 (8%).

26% of respondents have been infected less than or equal to 4 years. Overall, the greatest proportion of respondents (64.6%) has lived with HIV/AIDS for 5-14 years.

**Years of living with HIV/AIDS**

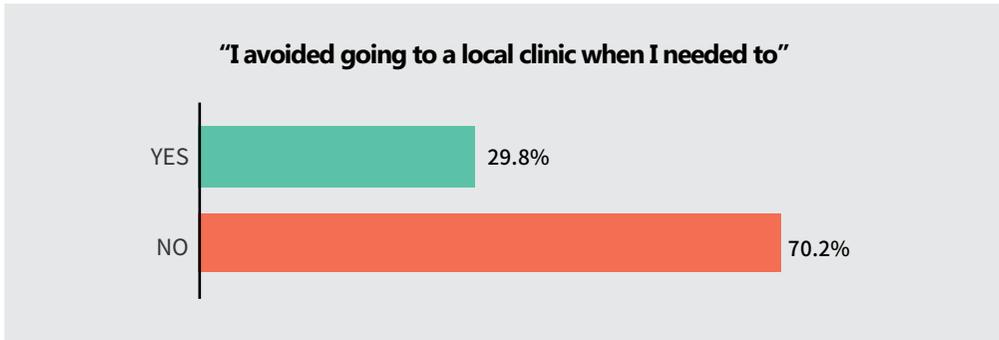
less than a year	2(1.9)
1-4 years	25(24.0)
5-9 years	39(37.5)
10-14 years	28(26.9)
more than 15 years	10(9.6)

The level of education of whole respondents is relatively high. Yet poverty is a serious issue among survey respondents. Although more than half of respondents have college education, the proportion in full-time employment at the time of the survey is only 36.5%.

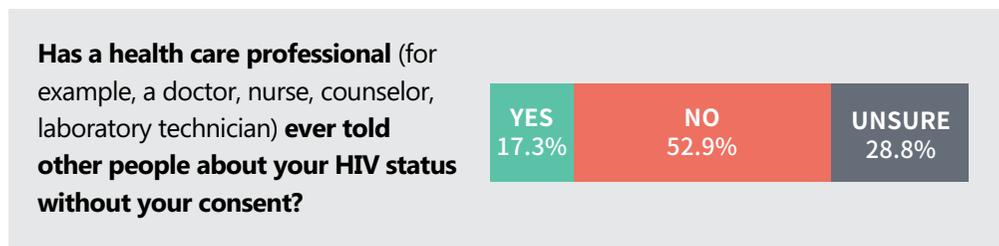
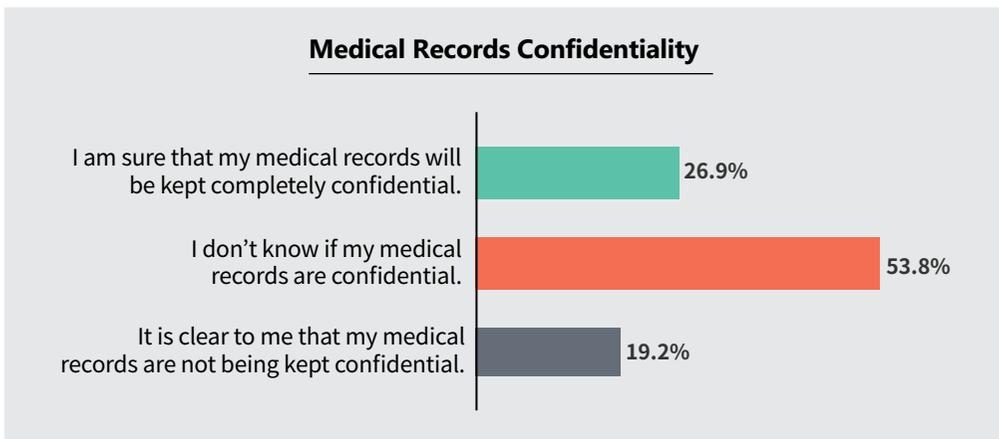
Around 50% of the total respondents are irregularly employed or unemployed, and 42% of the total respondents are living with less than the minimum household income, one million Won (875 USD) per month.

## 2. Experiences in Healthcare

Around 30% of respondents answer affirmatively that they rather forewent a necessary doctor's visit at least once in the past 12 months.



Only 27% of respondents are sure that medical documents about their HIV-infection are handled completely confidentially, 53.8% are not sure, and 19.2% find it obvious that confidential handling is not ensured. 17.3% of respondents even experienced the disclosure of their HIV status by medical professionals without their consent.



From the questions about HIV testing the following picture appears: 61.5% state that they were tested for HIV without their knowledge. And 64% of them are those who have been positive less than 10 years.

### Motivations for HIV testing

	%
<b>Tested during treatment unrelated to HIV</b>	26.0
<b>Referred due to suspected HIV-related symptoms</b>	23.1
<b>Blood donation</b>	15.4
<b>I just wanted to know</b>	13.5
<b>Employment</b>	6.7
<b>Health check-ups</b> (General check-ups, special check-ups of food handlers, employees in the entertainment sector, soldiers, and prisoners)	6.7
<b>Husband/wife/partner/family member tested positive</b>	2.9
<b>Referred by a clinic for sexually transmitted infections</b>	1.9

This pattern is related to the fact that more than half of respondents were tested during medical procedures. Only the 36.5% of respondents voluntarily took HIV test in order to know about their HIV status.

The proportion of respondents who received both pre and post HIV counseling is only 11.5%. 42.3% of respondents reported that they did not receive any kind of counseling during testing, and 44.2% received only post-test counseling. Pre-test counseling can be a crucial step to provide appropriate knowledge about HIV (including prevention messages for those who may be at higher risk) and to relieve any possible emotional stress, but only 13.5% of respondents received the counseling before testing.

### Was the decision to be tested for HIV up to you?

	%
<b>Yes, I took the decision myself to be tested (i.e. it was voluntary)</b>	36.5
<b>I was made to take an HIV test (coercion)</b>	2.0
<b>I was tested without my knowledge – I only found out after the test had been done</b>	61.5

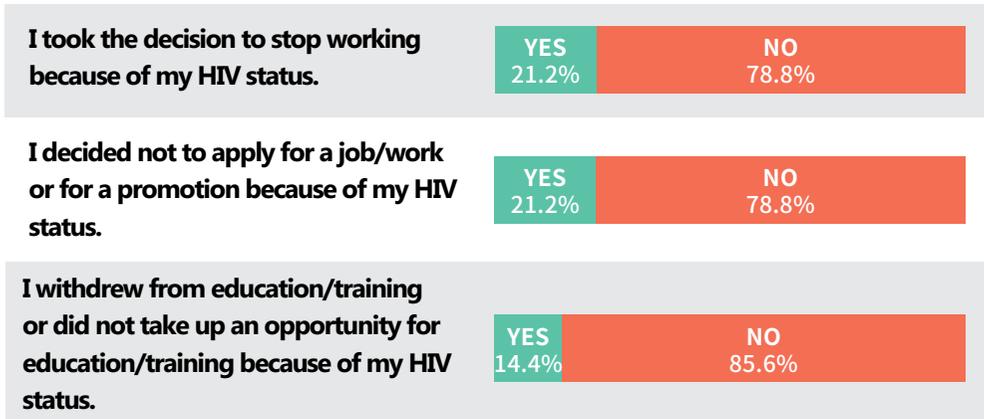
### HIV Test Counseling

	%
<b>I received both pre- and post-HIV test counseling</b>	11.5
<b>I only received pre-test HIV counseling</b>	2.0
<b>I only received post-test HIV counseling</b>	44.2
<b>I did not receive any counseling when I had an HIV test</b>	42.3

### 3. Work and Employment

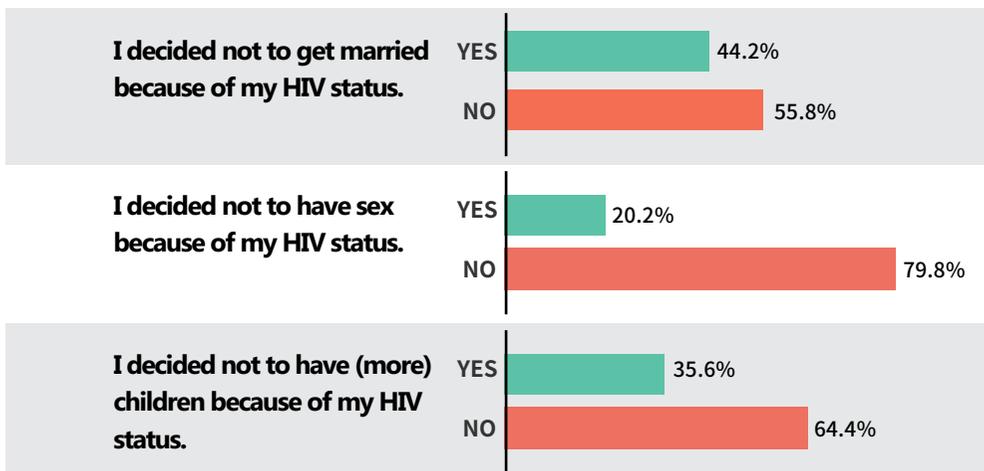
43.3% of respondents are full- or part-time employees. Only 8.9 % of respondents who were currently full- or part-time employed reported that they had disclosed their HIV status to their employer, and about half of them received discriminatory reactions.

More than the half of total respondents also reported that they decided to quit their jobs or gave up pursuing further education because of their HIV status.



### 4. Sexuality and Reproduction

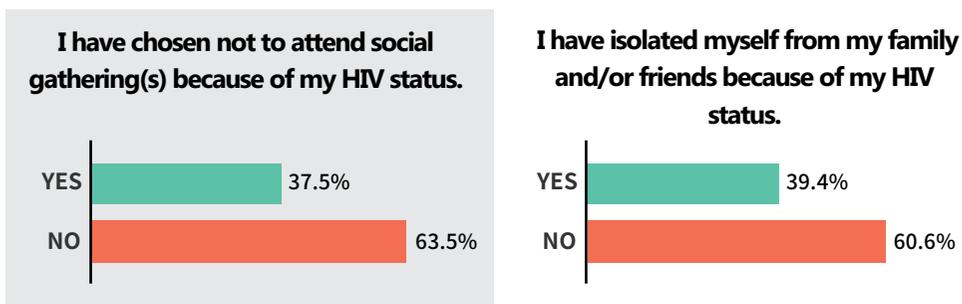
20% of respondents state that they abstained from sex because of their HIV status at least once in the past year. In terms of abstaining from sex, the percentage of men under 40 is slightly higher than those over 40.



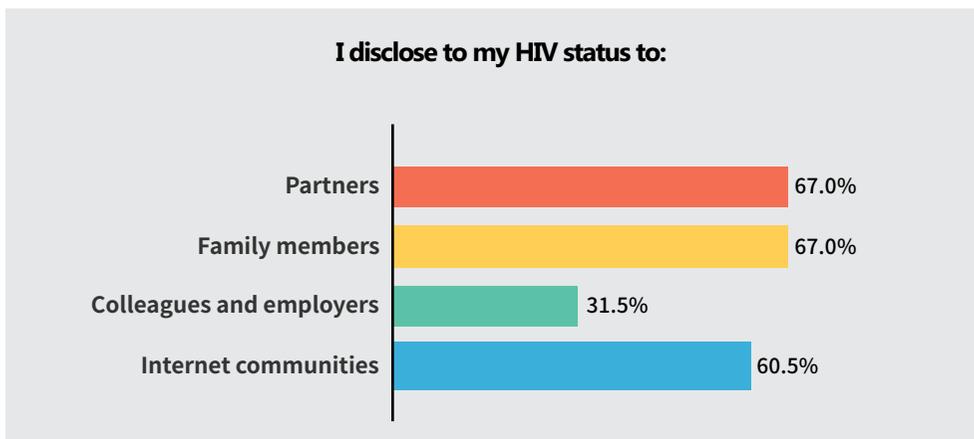
# 5. Openness with HIV status

67 % of respondents state that they are open about their HIV status with their partners and family members, and 31.5 % are with their colleagues and employers. 21% of respondents rather decided not to disclose their HIV status to anyone, because all of them anticipated discrimination or negative responses toward them.

Almost 40% of respondents state that they have isolated themselves from their own family and/or friends. Such discrepancy between direct discrimination experiences and interpersonal interactions indicates that social isolation is a common and serious symptom of stigmatization.

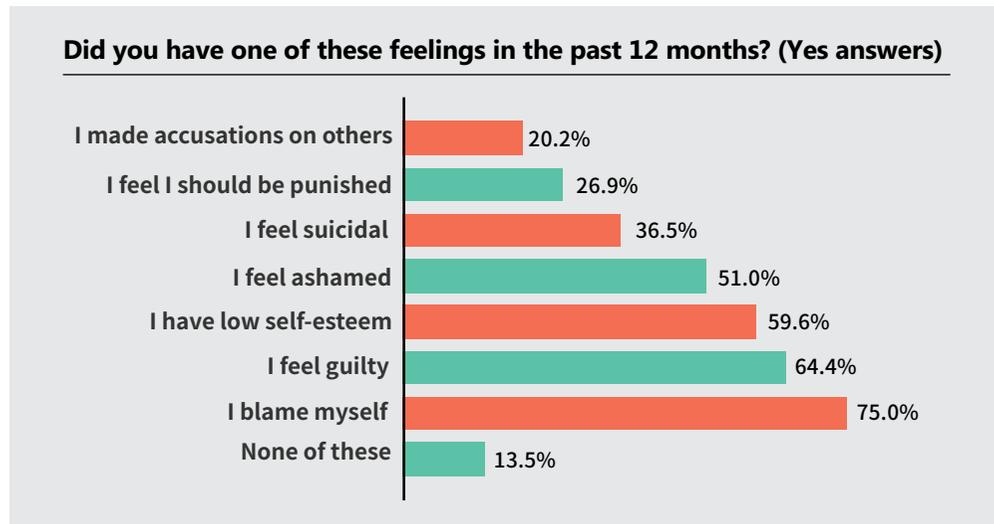


Most respondents disclose their HIV status to their partners and family members out of obligation. Besides, almost half of the respondents who revealed their HIV status to the Internet community mentioned seeking emotional support as the main reason of their disclosure.



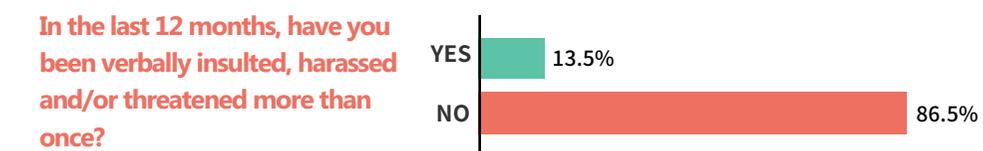
## 6. Internalization of Stigma

75% of all respondents felt self-blame due to their HIV status at least once in the past 12 months. 64.4% stated having feelings of guilt, and 59.6% reported having low self-esteem. 26.9 % also agreed with the statement "I had the feeling I should be punished". It is also striking that 36.5% of respondents reported that they have had suicidal thoughts. Only 13.5% stated that they experienced no negative feelings in connection with their HIV status in the past 12 months.



## 7. Rights and Social Environment

25% of respondents reported having being gossiped behind their back, and 76% among them attribute this directly due to their HIV status. 13.5% of respondents also stated having been verbally offended in the past 12 months, and 71.4% among them say that this happened in connection to their HIV status.

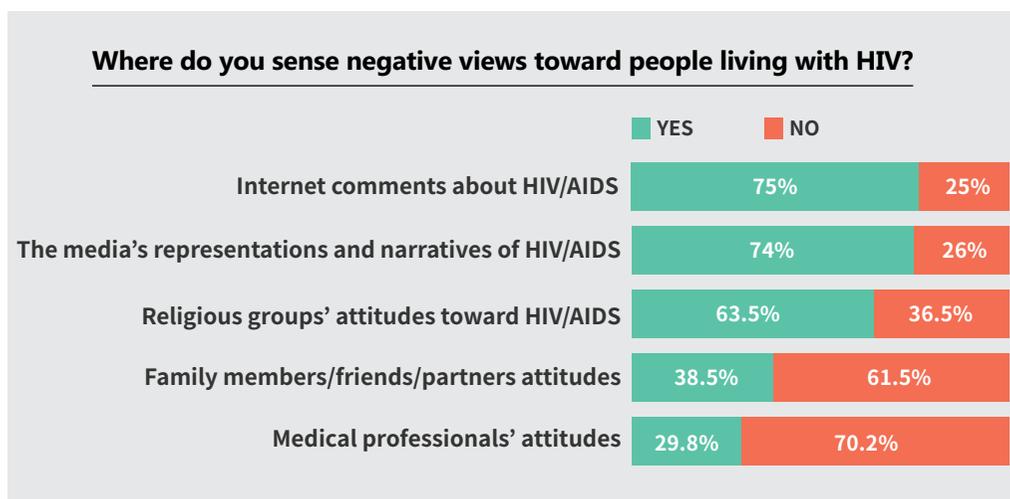


12.5% of respondents reported that they were denied insurance in the past 12 months. 6.7% of respondents also stated that they were given medical treatments or examinations without their consent. 4.8% had to disclose their HIV status to enter other countries.

**In the last 12 months, have any of the following things happened to you because of your HIV status?**

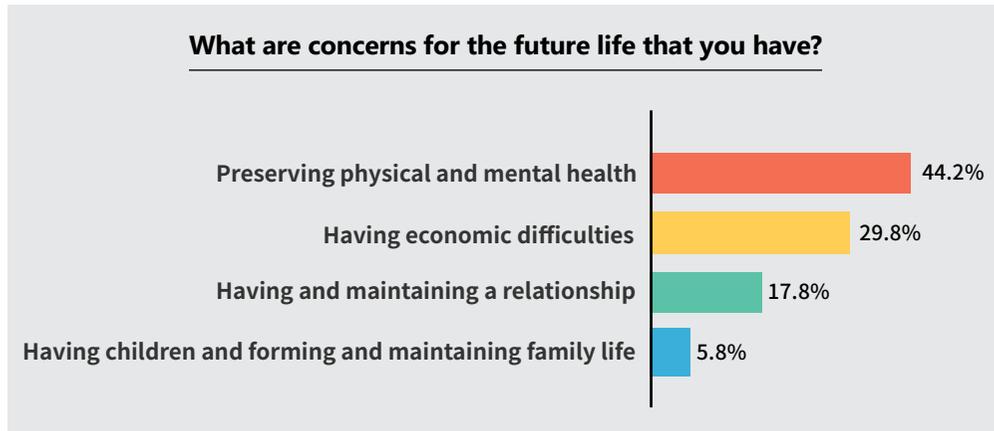
	%
I was forced to submit to a medical or health procedure (including HIV testing)	6.7
I was denied health insurance or life insurance because of my HIV status	12.5
I had to disclose my HIV status in order to enter another country	4.8
I was detained, quarantined, isolated or segregated	1.9

Beside these violations, respondents expressed that they sensed negative attitudes toward them in several social sectors. More than 70% of respondents stated that the media space including both the public media representations and the Internet comments provide unfavorable views toward people living with HIV/AIDS. Religious groups' approaches toward HIV/AIDS are also viewed as hostile.



## 8. Effecting Changes

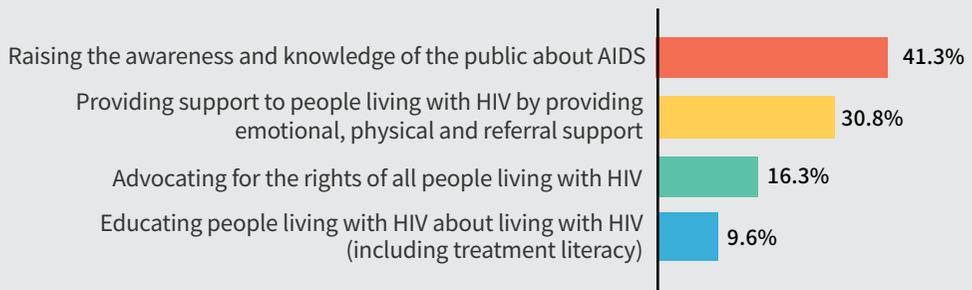
What are concerns for the future life that respondents have? 44.2% of respondents said that they were concerned about preserving their mental and physical health. Around 30% of respondents also worried about having economic difficulties.



When problems associated with stigma and discrimination arise, the majority of respondents said that they would get in touch with HIV support groups to ask assistance. It is also important to note that more than half of respondents mentioned HIV/AIDS counseling nurses as a source of help.



**What is the most important thing that HIV/AIDS organizations and initiatives need to do in reference to discrimination and stigmatization?**



# Concluding Discussions

## : New Voices from Unknown Territory

More than 30 years on from the start of the HIV epidemic in South Korea, the reality of living with HIV is still unknown. As the first peer-led research on HIV in this country, the "People Living with HIV Stigma Index Project in South Korea" aims to map out this unknown territory of life. Although effective HIV treatment has been available in South Korea from the early stage of the epidemic such that an HIV diagnosis needs not be a death sentence, stigma and discrimination against people living with HIV still remain pervasive. Through this research, we try to amplify the unheard voices of the ordinary people living with HIV.

The main limitation of this research is that our survey sample size is not big enough to be statistically representative of all people living with HIV in South Korea. Considering the fact that around 10,000 people are reported HIV positive in South Korea, only 1% of them are reached through this research due to lack of resources and government support. Another limitation of this research is the under-representation of a certain section of the populations who are affected by HIV. Although this survey well reflects gay populations' experience of HIV epidemic in South Korea, women's experience is unrepresented in this research. Other under-represented groups in this research include the transgender populations and migrant communities. Further research is required to fully understand how heterosexual, transgender, non-native Korean, and rural populations are affected by HIV and AIDS related stigma.

The main findings of this research are:

### **Poverty is impacting people living with HIV.**

While the general level of education of survey respondents is slightly higher than that of the general population, the employment situation of them is precarious. Around 50% of the total respondents are irregularly employed or unemployed, and 42% of the total respondents are living under the minimum household income. Dependence on welfare benefits is also confirmed from in-depth interviews. Several of life history interviewees expressed the emotional distress and economic difficulties of relying on benefits from the National Basic Living Security. Unemployment and poverty is seriously impacting people living with HIV. **Such finding calls for a re-evaluation of the current benefit system for people living with HIV who are unable to work or work full-time. More research on how to strengthen anti-discrimination protections in workplaces is also needed.**

### **Violations of privacy protections are prevalent.**

Almost 100% of survey respondents answered that they were currently receiving antiretroviral treatment. Yet survey respondents are largely uncertain that their privacy is protected in healthcare settings. Less than 30% of survey respondents were confident about that their medical documents containing information about their HIV status are handled completely confidential. Such low trust is also related to the fact that 17.3% of the respondents reported that their HIV status was disclosed by healthcare professionals without their consent. It shows that there is a high chance that people with HIV experience violations of privacy during the routine procedures of detection, testing, reporting, and receiving treatment. The impact of this can be seen in the high numbers of people who reported that they had avoided going to hospitals and clinics for necessary treatment because of their HIV status. Although the AIDS Prevention Act includes confidentiality and anti-discrimination protection clauses, people with HIV in South Korea do not enjoy guaranteed protection of their privacy. Protection of privacy of people living with HIV is crucial for protecting their basic rights to prevention, treatment, and care.

**Systemic training for healthcare providers on HIV and AIDS should be implemented with a special focus on patients' rights. Stronger measures and penalties also need to be imposed to prevent privacy violations and ensure access to justice for those who experience rights violations.**

### **HIV testing needs to be more carefully planned and expertly executed.**

The survey results show that the international standards on voluntary and confidential testing and counseling are not fully implemented in South Korea. Only 11.5% of respondents received both pre- and post-HIV test counseling, and more striking is that 42.3% did not receive any form of counseling when they had an HIV test. It means that most people learned about their HIV status without proper preparation and knowledge. Such testing pattern reflects the fact that 61.5% of respondents stated that they were tested without their knowledge, mostly during medical procedures. In-depth interview findings also confirm that the sudden informing of their HIV status was deeply traumatic experience. HIV is still a highly stigmatized disease, and pre- and post-HIV counseling can be an effective tool to provide adequate knowledge about HIV, to support the clients to be able to cope with immediate and intermediate emotional and social implications, and to break down the stigma so as to enable a more effective public health response.

**World Health Organization (WHO) also strongly recommends that HIV testing should include counseling (pre-test information and post-test counseling) and provide linkage to appropriate treatment and support services. The national guidelines for voluntary and confidential HIV testing and counseling need to be developed and implemented in accordance to WHO's consolidate guidelines for HIV testing.**

### **The negative effects of internalized stigma have reached a critical level.**

More than half of all survey respondents reported having high levels of self-stigma. Only 13.5% of respondents said that they did not have any internalized stigma related to their HIV status. The sense of self-blame, guilt, and low self-esteem were commonly stated as major internal feelings they have. The percentages of people having suicidal thoughts are also alarmingly high (36.5%). In comparison with other countries' Stigma Index Report, the level of internal stigma found in South Korea is particularly serious. According to Global Stigma Index data set, among 6 countries (including Thailand, India, Republic of South Africa, Uganda, and Germany), Korean respondents show the highest level of agreement with six different negative feelings. The percentage of respondents who have self-blame (75%) and who report a fear of gossip (78.8%) is also extremely high compared to these countries.

The link between internalized stigma and social isolation is also confirmed. Significant numbers of respondents decided not to pursue further education or career since their diagnosis. Such tendency of withdrawal from social interactions is also found in the family and sexual life. Almost 40% of respondents say that they have isolated themselves from their family and friends; and 20% of respondents decided not to have sex because of their HIV status.

**HIV organizations, healthcare professionals, and government agencies in South Korea should consider internal stigma as a serious health and social hazard and actively respond to it. Internalized stigma hampers infected people's capacity to live within the society and deepens their isolation. A join national strategy against HIV stigma should be implemented in partnership with people living with HIV, government agencies, civil society organizations, and healthcare professionals.**

## Stigmatizing and disempowering messages are rampant.

The high level of internalized stigma signifies that people living with HIV in South Korea are repeatedly exposed to the negative attitudes toward them. More than 70% of survey respondents stated that they felt that the public media's views and remarks on them were derogatory. It is also important to note that 63.5% of people agreed with that religious groups contribute to spread negative views of people living with HIV. Such results are interrelated with routine exposures to HIV myths and stigmatizing languages.

As there has been no national HIV campaign launched for the general population since 2004, ill-informed and discriminatory messages are deeply damaging to people living with HIV. We are facing with the urgent task of how to battle against stigmatizing language routinely found in public discourses. **National level campaigns should be launched to provide up-to-date knowledge and information about HIV and to confront discrimination against people living with HIV and sexual minorities.**

## Positive Voices

*"By participating in the Stigma Index Project last year, I began to face up to the real problem of discrimination and prejudice toward HIV. Now I start to working for the Korean Gay Men's Human Rights Group as an HIV activist. The organization welcomed me, and it really made me stronger. One day, South Korea will be the place where people living with HIV can live like normal people. I hope that people living with HIV also overcome their own internal stigma and start seeking help from the outside. A lot of things can be changed."*

**Field Researcher, Seoul, April 2017**

As the first peer-led research, the South Korean Stigma Index is the initial step to push for change to ensure that the needs of people living with HIV and AIDS are fully met. This research becomes possible through the self-organization of affected people, and it gives hope. All field researchers who did survey and interviews expressed a deep sense of satisfaction and encouragement in community organizing. The very experience of being a researcher for their own problems, rather than being an object of research turned out to be an empowering experience. Survey respondents and in-depth interviewees also valued field researchers' interests and concerns toward them, and conducting research itself has been a process of community organizing. As this research offers a rare chance to focus on gay males' experience of living with HIV in South Korea, the gap between HIV communities and sexual minority communities is also bridged. This research also proves that the current HIV/AIDS organizations in South Korea have a capacity to organize professional research activities and cooperate with international agencies. In South Korea, the diverse voices of people living with HIV have long been absent in policymaking and public discussions. This is the very time to let their voices be heard.

# Recommendations

1. 한국 사회에서 HIV/AIDS에 대한 낙인은 감염인에게 직간접적인 폭력을 야기한다. HIV 감염은 생물학적 상태이자 사회적 장애로 존재하며, 이에 대한 낙인은 성소수자, 여성, 성노동자, 외국인에 대한 낙인과 밀접히 연결되어 있다. 국가는 HIV/AIDS에 대한 모든 정책에서 감염인 및 관련 취약집단에 대한 사회적 낙인을 없애고 차별을 금지하는 것을 중심 목표로 설정해야 한다.

1. In Korean society, the stigma attached to HIV/AIDS acts as violence against people living with HIV in a direct and indirect manner. HIV is not only a biological condition but also constitutes social disabilities. Moreover, the stigmatization of HIV/AIDS is closely associated with the stigmatization of women, sex workers, and foreigners. The South Korean government should prioritize the elimination of social stigma and the prohibition of discrimination against people living with HIV as their primary goal.

2. HIV 감염인이 가족의 구성원이자 경제 행위자, 시민으로서 자신이 가진 최대한의 역량을 발휘할 수 있도록 노동권, 사회권이 보장되어야 한다. 이를 위해 직장 내 HIV 집단 검사 및 감염을 근거로 한 고용상의 차별과 해고는 엄격히 금지되어야 한다. 또한 감염인의 사회적 권리 보장 및 차별 금지의 실질화를 위해 HIV 감염을 『장애인 차별금지 및 권리구제 등에 관한 법률』에서 정하는 장애의 범주로 포함하는 방안 역시 적극적으로 검토될 필요가 있다. 또한 포괄적인 형태의 차별금지법 제정을 통해 병력에 따른 인권 침해 및 차별 요소를 개선해야 한다.

2. Labor rights and social rights should be guaranteed to people living with HIV, so they can exercise their full capacity as members of the family, economic agents, and citizens. Accordingly, the discrimination and termination of employment based on their HIV status and compliance with HIV testing in the workplace should be strictly prohibited. It is also necessary to explore ways to consider HIV as a condition of disability that is under the protection of the “Act on the Prohibition of Discrimination of Disabled Persons, Remedy Against Infringement of their Rights, etc”. Finally, a comprehensive form of anti-discrimination law should be enacted to thoroughly address human rights violations and to prevent discrimination.

3. 한국의 HIV/AIDS 정책은 전염 통제 중심의 관리 정책에서 벗어나서 HIV 감염의 조기 진단과 감염인의 행복한 삶을 목표로 하는 인권 중심의 예방 패러다임으로 전환되어야 한다. 또한 생애 주기 전반에 걸쳐 HIV/AIDS에 대한 교육과 공공 서비스를 제공해야 한다. 이를 위해서 청소년을 대상으로 한 성교육에 인권에 기반한 HIV/AIDS 교육 및 성적 다양성에 대한 정보가 반드시 포함되어야 하며, 감염 인구의 노령화에 대처하기 위한 장기적 로드맵을 마련하여야 한다.

3. HIV/AIDS policies in South Korea should change their current focus on infection control to a human rights-centered approach that promotes early HIV diagnosis and the wellbeing of people living with HIV. HIV education and services also should be available at all different life stages. For instance, sex education for adolescents should contain information regarding HIV in general as well as the diversity of sexual orientations. A long-term roadmap to cope with aging HIV populations is also needed.

4. HIV 검진은 감염인을 찾아내는 수단이 아니라 질병에 대한 올바른 정보를 전하고 확진 판정을 받은 감염인에게 지지 체계를 마련해줄 수 있는 과정의 하나로 설계되어야 한다. HIV 검사 전후 질병의 진행 과정과 낙인의 문제에 대한 심층적인 교육과 상담이 필수적으로 이루어져야 하며, 이를 지원하는 상담간호사, 동료 감염인 상담사와 같은 전문 인력이 확충되어야 한다. 또한 응급 상황에서 검사 전 상담의 과정을 거치지 않고 HIV 검사가 이루어졌을 경우, 당사자의 충격을 감안하여 충분한 정보와 정서적 지지를 제공할 수 있도록 감염 사실 고지 과정에 더 많은 주의를 기울여야 한다.

4. HIV testing should be designed in order to provide a support system for those with a confirmed diagnosis. Pre- and post-test counseling should be provided addressing stigma-related issues, and regular and standardized trainings should be available for medical and technical staff who are involved in testing and counseling. In the event of an emergency where an HIV test has to occur in the absence of a prior consultation, extra attention must be paid in consideration of the client's vulnerable state.

5. HIV 예방 및 치료에 참여하는 의료인, 공무원, 보건 종사자는 감염인과의 접촉이 가장 빈번한 집단일 뿐만 아니라 감염인들이 자신의 감염 사실을 밝히는 첫 번째 대상일 가능성이 높다. 이들은 자신의 직무과정을 통해 낙인이 강화될 수 있다는 점을 이해하고, 감염인의 인권 보장을 위한 조치를 숙지해야 한다. 특히 직무 수행의 전 과정에서 보편적 주의 지침(universal precautions) 및 감염인에 대한 비밀 준수의 원칙이 지켜져야 한다.

5. Health care workers, civil servants, and health practitioners participating in the prevention and treatment of HIV/AIDS will most likely be the first to identify an individual's HIV status. Therefore, they should understand that the stigma of HIV/AIDS can be exacerbated by their own conduct and be constantly mindful of their responsibility to promote the human rights of people living with HIV. In particular, confidentiality of HIV status and universal precautions must be observed throughout the entire duration of care.

6. HIV 감염인에 대한 진료 거부 및 병원 내 차별 행위를 근절할 수 있는 법적, 제도적 장치가 시급히 마련되어야 한다. 사실상 대부분의 요양병원에서 HIV 감염인의 입원을 거부하고 있는 상황에서 실효성 있는 차별 구제 수단의 도입없이 개선을 기대하기 어렵다. 국가는 장기 요양이 필요한 감염인이 필요한 서비스를 받을 수 있도록 의료 기관 및 의료인에 대한 교육과 관리 감독 방안을 마련해야 한다.

6. There is an urgent need to forbid the refusal of treatment based on the patient's HIV status. The current situation that most nursing homes in South Korea tend to refuse the admission of HIV patients reveals that without adopting strong anti-discrimination measures, it is impossible to ensure HIV patients' right to access long-term care. The government should adopt strong measures to supervise medical institutions and health care professionals to ensure HIV infected persons continue to have access to treatment and care.

7. 군대, 수감시설에서 고립된 단체생활 중이거나 신체적, 정신적, 인지적 장애를 가진 감염인들이 사생활을 보호받을 권리와 치료받을 권리, 정보에 접근할 권리가 충분히 보장되도록 이들을 위한 프로그램을 만들 필요가 있다. 수감시설을 포함한 공동생활시설에서 사전 동의 없는 집단 검진은 금지되어야 하며, 특히 군복무 중 HIV 확진 판정을 받을 경우 비밀 보장의 원칙 하에 필요한 서비스에 접근할 수 있도록 하는 실질적인 지침이 도입되어야 한다.

7. It is necessary to adopt national guidelines for people living with HIV who are isolated in the military and detention facilities in order to ensure their rights to privacy, treatment, and access to information are protected. Mass testing without individual consent should be prohibited in these collective residential facilities, and private testing and counseling services should be institutionally guaranteed especially for those who are in the mandatory military service.

8. 전파매개행위 금지 및 처벌조항은 감염인의 성적 자기 결정권을 침해하는 것은 물론 HIV 전염을 범죄화함으로써 낙인을 제도화한다. 이러한 불필요한 규제는 조기 검사와 정기 검사를 통한 감염 확인의 자발적 동기를 약화시킨다는 점에서 예방적 차원에서도 부정적 효과를 낳는다. 현 『후천성면역결핍증 예방법』의 전파매개행위 금지 및 처벌조항은 반드시 삭제되어야 한다.

8. The current "AIDS Prevention Law" that prohibits and criminalizes HIV transmission must be amended. Such penalizing approach does not only undermine the sexual self-determination of people living with HIV but also perpetuates HIV stigma. The criminalization of non-HIV disclosure also brings negative effects on prevention, as it discourages early and regular HIV testing. The existing clause that criminalizes HIV transmission should be removed from the AIDS Prevention Act.

9. HIV/AIDS에 대한 혐오 표현은 언론의 자유에 포함될 수 없다는 점을 분명히 하고, 질병에 대한 공포와 편견을 조장하는 행태에 대한 적극적인 규제가 이루어져야 한다. 언론 매체 및 온라인 공간에 대한 상시적 모니터링과 함께 HIV/AIDS와 감염인에 대한 편견을 조장하는 혐오 표현에 대한 실질적인 처벌 규정이 마련되어야 한다.

9. Hate speech aimed at people living with HIV should not be tolerated, and any ill-informed report that disseminates fear and misconception related to HIV and AIDS should be regulated. Regular monitoring of the media and online platforms, as well as appropriate control of hate speech that provokes discrimination against people living with HIV should be enacted.

10. 우리는 감염인 자조모임과 당사자 활동이 감염인 상호 간의 정서적 지지, 양질의 정보교환, 사회적 자아의 발현에 중요한 역할을 한다는 사실을 인식하고 있다. 따라서 감염인 자조모임과 당사자들이 사회의 일원으로서 기여할 수 있도록 지원해야 하며, 특히 에이즈 정책의 구성과 결정 과정에 직접 참여할 수 있도록 해야 한다. 성소수자 공동체 역시 HIV/AIDS 낙인의 문제에 적극적으로 대응해야 한다. 공동체의 중요한 구성원으로서 감염인의 사회적 욕구를 파악하고, 이들의 주변화 문제를 해결하기 위해 나서야 한다.

10. We recognize that social networks of people living with HIV are key in providing mutual emotional support, exchange of information, and a sense of social membership. It is crucial to support HIV organizations and self-help groups and ensure their participation in HIV/AIDS related policymaking processes. In combating HIV stigma, the collaboration between HIV networks and sexual minority communities is also crucial. We need to build a wider social network that takes into account the social needs of people living with HIV and prevents marginalization based on stigma.

# Unknown Lives

Initial Findings From *The People Living with  
HIV Stigma Index In South Korea 2016-2017*