Report

Index of Stigma and Discrimination against People Living with HIV/AIDS in Thailand

Thai Network of People Living with HIV/AIDS (TNP+)

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Executive Summary

Index of Stigma and Discrimination against HIV-positive People

This research study on index of stigma and discrimination against HIV-positive people was aimed to promote and support the advocacy of human rights issues in Thailand. It was implemented by the Thai Network of People Living with HIV/AIDS (TNP+) and supported by the Joint United Nations Programme on HIV/AIDS (UNAIDS). The research team comprises lecturers from the Faculty of Arts, Ubon Ratchathani University and 13 members of HIV-positive networks from all regions of Thailand. The preparatory process began in February 2009. A total of 233 respondents were recruited, of whom 148 were women, 57 were men and 28 were of other sexual diversity. The data collection process was completed in June 2009. The initial analysis was presented to members of all the 7 positive networks at regional assemblies during September 2009 – January 2010. Another 4 presentations were given to government authorities, private agencies and different civil society groups in November 2009 in Rayong, Khon Kaen, Songkhla and Chiang Mai provinces.

This research study employed a questionnaire adapted from The People Living with HIV Stigma Index jointly developed in 2005 by:

1. The Global Network of People Living with HIV/AIDS (GNP+)
2. The International Community of Women Living with HIV/AIDS (ICW)
3. The International Planned Parenthood Federation (IPPF)
4. The Joint United Nations Programme on HIV/AIDS (UNAIDS)

Not only did this index study bring forth a collection of evidence, it empowered positive people and fostered Greater Involvement of People Living with HIV/AIDS (GIPA), the principle for and goal of social movement by people affected by HIV infection. Findings acquired through this project can enable both Thailand and other countries to understand these prevailing social phenomena in conjunction with national rights-related policies, inform program design aiming to resolve and reduce HIV stigma and discrimination issues at implementation level, and advocate for national-level policy.

Data collection took place in mid-2009 through interviews to gather past experiences of positive people in different parts of Thailand. Therefore, the data recorded were incidents that occurred between 2008-2009. Some of them were terms used, gestures and expressions showing stigma, overlapped with other statuses such as being women, drug users, children of positive parents, people having different sexual identities from their biological sex, sex workers, homosexuals, ethnic minorities and migrant workers. Stigma was also coupled with "promiscuous" behaviors which are sexual bias that nurtures transmission as it only addresses HIV from epidemiological perspective and focuses on the control of the virus from spreading. As a result, these positive people were deemed as deserving control over their life and discrimination in order to ensure safety for the society at large.

The word "stigma" in this research means an action that tarnishes, and creates dehumanization because of sexual misconduct, sexual bias or the otherness attached to the inferior, i.e. ethnic groups or migrants. This stigma index relates to HIV status and double stigma. Some forms of stigma identified include being homosexuals, sex workers, drug users, inmates, ethnic minorities and migrant workers. The designation of a set of values to relationships in the forms of "culture" and "morality" in the Thai society led to self stigma, causing positive people to think they are indecent, amoral and therefore deserve to be stigmatized and discriminated against. To avoid stigma and discrimination, they had to keep a low profile and

isolate themselves from others. This research revealed that some respondents thought they did not have any stigma and discrimination experiences because they did not socialize with others. However, the feelings of guilt, modesty, frustration and desire to commit suicide (39 out of 233 total) were present. These feelings reflect the magnitude and intensity of stigma on positive people. Self stigma index included but not limited to **shame, guilt, self-blaming, blaming others, desire to commit suicide, lower self-esteem, yielding to punishment, fear of being gossiped, slander, harassment, assault or refusal**.

Discrimination is an index suggestive of stigma and directly affects positive people themselves and those associated with them. Discrimination at policy level contributes to the impracticality of certain policies, i.e. rejection of employment or being last to be served health services despite equality manifestation and showing up early. In the case of reproductive health services, respondents were told to avoid pregnancy, undergo sterilization and be restrictive on their couple life. From a relevant aspect, they faced verbal objection, physical oppression, gossip, prejudice look, refusal to attend school, termination of employment, being driven away from a rented house, or undesirable disclosure.

This research study confirmed that discrimination indices found were in line with those used to construct the questionnaire developed by international partners. These include:

1. Living with a family, i.e. being denied living in the same house, refused having sex with, or psychological, verbal and physical assaults.
2. Living in the society, i.e. being gossip targets, verbal and physical harassment, physical assault, or intimidation.
3. Employment, i.e. loss of jobs, income, promotion opportunity, decision not to apply for a job or self-denial to be considered for promotion.
4. Lack of access to healthcare services, i.e. refusal of treatment provision, inability to access birth control or reproductive health services.
5. Deprivation of education, i.e. rejection of application or be forced to leave school.
6. Violation of rights, i.e. involuntary blood testing and counseling, blood result notification and disclosure of HIV status with or without consent.
7. Inability to access rights protection and information; lodge a complaint, face, challenge and educate actors of stigma and discrimination.

This research achieved the 3-bird goal; namely, "building capacity" with implementation skills through hands-on field experiences, "developing index" to provide tangible evidence of factors and conditions contributing stigma and discrimination, and "building mechanism for rights movement" to foster a multilateral effort by stakeholders that include both government and private sectors, enable the Thai positive network to establish regional rights working groups and to develop a strategic plan on rights advocacy.

They key four findings from this research include the following.

1. Stigma and discrimination have persisted in the Thai society yet in more diverse and complex forms.
2. Stigma and discrimination in family, community and violence in daily life continuously occur, whether the actors are intentional and the victims are cognizant of the incidents or not.
3. There is a high level of self stigma among HIV-positive people.
4. Protection of rights is unrealistic and hard to achieve in the eyes of positive people.

The perception that rights are an imported conception from the West should not persist. It should be understood that rights are about rules and regulations for people in the same society to observe. The existence or insecurity of rights affect direction and wellbeing of the society at large and the people living in it. Thus, rights are not something that is "imported" into the Thai society. Nonetheless, rights in different contexts have different scopes and extents. For instance, "human rights" are fundamental rights every human deserves, citizens are entitled to their rights under the governing of a state, community rights, etc.

Recommendations

1. Positive networks should take part in providing acquisition of and initiating a learning system of rights issues in the Thai society in order to fine-tune relevant attitudes into a new culture. They should also advocate for legal reform as part of the realization of rights-conscious culture.
2. Advocacy for rights issues must be concerted. The research team realized that stigma exists diversely and continuously in our daily life. It can be categorized into two broad groups; stigma that is linked to society's moral standards and stigma resulting from the designation or classification of good/bad qualities, leading to the otherness being attached to anyone deemed as deviant or nonconforming. Therefore, the rights movement in the Thai society must take into consideration all relevant aspects, i.e. AIDS rights, sexual rights, citizenship rights, etc. It should not be an effort solely focusing on one aspect but include social and cultural contexts for social bias against positive people does not derive from HIV alone. It is linked to and fueled by pre-existing bigotry especially toward "sex" and behaviors regarded as "nonconformist", "abnormal" and "amoral".

To overcome the barriers of stigma, discrimination and rights violation that have firmly rooted into the society, it takes the efforts by positive people themselves. In addition, biases regarding sex, ethnicity, social status, etc., must also be defeated. However, fighting these cultural prejudice and bias should not fall on the shoulders of positive people alone. All parties concerned must be open to join hands and to learn from positive people and victims of stigma and discrimination who have been striving to unshackle this cultural chain that has tethered and oppressed them.

Stigma Index

Chapter 1

People Living with HIV: Stigma, Discrimination and Rights

It's probably true that stigma against people living with HIV started when Thai people first learned of the term AIDS.

No healthcare providers had thought prevention campaigns propagating such catchphrases as "AIDS equals death & incurable", "promiscuity means AIDS (and death)" and "sharing needles & free sex equal AIDS" would have brought those infected with HIV to suffer.

When someone is diagnosed as having AIDS, it's like living death for them.

Photos of AIDS patients showing blisters and emaciated bodies have become a representative reality for anyone living with HIV and led to social misperception between "AIDS patients" and those having HIV in their bodies or "HIV positives".

In fact, HIV itself does not hurt those living with it as much as social judgment does. People with AIDS are branded as immoral because of behaviors deemed as promiscuous . They are regarded separate and different from others who are considered normal and as a result are terminated from employment.

These prevention campaigns aimed at creating public fear of AIDS in order to control and contain it from spreading. However, after a long period of time, not only have these well-intended "mantras" failed to reduce infection rates, they have caused widespread impact on the relationship between positive people and their negative counterparts in the society. Worse, they have profoundly rooted in the society.

This silent aggravation of stigma against people living with HIV/AIDS has continued to these days. Despite the World Health Organization (WHO) declaration in 2003 which emphasizes the need for prevention in parallel to care and treatment in the response to HIV/AIDS and a change in social attitude toward HIV/AIDS and the reduction of stigma and discrimination in every society, negative stereotypes attached to people living with HIV/AIDS continue to prevail in the Thai society, as exemplified in the following.

"Our organization stresses the importance of condom use among the risk groups…."

"Thai men risk contracting HIV by opting for transvestites for there's no need to worry about pregnancy and condom use…."

These examples of labeling positive people as homosexuals or classifying them as the risk group reflect the prevailing of social stigma as a norm in the Thai society.

Once someone has HIV in their body, they are immediately sentenced on charges of personal sins, being immoral or having committed wrongdoings, hence resulting in their infection. Moreover, sexual deviance, be it male homosexuals, male or female sex workers, male clients or injecting drug users, etc., (Tawat Maneepong, 2003), causes a stereotype that all HIV-positive people are sinned.

All the said issues above have resulted in a study on index of stigma and discrimination against people living with HIV/AIDS in support of human rights advocacy in Thailand. The study was implemented by the Thai Network of People Living with HIV/AIDS (TNP+) with financial support from the Joint United Nations

Programme on HIV/AIDS (UNAIDS) and collaboration from a group of 13 individuals consisting of lecturers from Ubon Ratchathani University and positive network representatives from all regions of Thailand[1].

Stigmatizing and respecting people living with HIV is a critical issue. There still remains hidden agenda in relation to the co-existence between positive people and their negative counterparts as positive people and their families are still treated with prejudice and different from the way general people are. Discrimination, refusal of children born of positive parents into school and terminating those infected with HIV from employment continue to exist, hence an attempt by TNP+ to conduct a study on index of stigma and discrimination against people living with HIV/AIDS in Thailand. The study was to be used as a tool to raise awareness and build understanding about stigma, discrimination and human rights for the study team members who are the core leaders of the positive networks at both regional and national levels. It was also to be used as a database for designing and setting the direction in driving the agenda regarding rights of positive people in Thailand.

Stigma, the raining stones

What is stigma?

To some, stigma is compared to raining stones falling on the body. Yet deep down, it makes one's heart suffer more than physical pain they feel.

According to Ban Ki Moon, Secretary general of the United Nations, stigma causes anxiety and fear for people living with HIV/AIDS to disclose their status to the public. Many do not have the courage to seek treatment despite the presence of symptoms beyond the extent they or their family can cope with. Thus, stigma has made AIDS the "silent killer".

Stigma is a conception used to explain cultural relationship that rejects, discriminates or stereotypes those having characteristics, behaviors or physical appearance that are different from cultural norms.

Stigma exists in different forms and at various levels. Rules and regulations imposed by a state may hinder positive people from entering into the country or require them to undergo a blood test. Healthcare staff may treat positive people differently from general patients without proper reasons, i.e. wearing an extra pair of gloves over another or wearing gloves every time when they have to touch the body of a positive person who has not progressed to AIDS. Stigma in the business sector happens in the forms of prejudice or refusal of association whereas gossip and disparagement may prevail in the community. Lastly, their own family may stigmatize against positive people either intentionally or vice versa.

Usually, stigma derives from at least three negative forms of cultural recognition. First, stigma exists against those having physical appearance different from the majority. This may include having a skinny body, leprosy, rashes, blisters or swelling on the skin. Second, stigma happens against people with symptoms or signs of illness or ailing physical conditions, i.e. those with mental disorders, alcohol addicts or substance abusers. Third, stigma can be influenced by ideology, bias or prejudice against social class, race or ethnicity. For example, calling Chinese as "chinky" or unequal treatment of hill tribes and ethnic groups in Thailand.

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[1] See project details and list of researchers and advisory board in the annex.

Stigma is complex and needs to be looked at with sensitivity. The difference between Pa-Dong (long-necked Karens), an ethnic minority in northern Thailand and westerners married to Thai women, especially to those from the Northeast, presents a case example. The society seems to accept or have minor negative reactions toward the westerners. On the contrary, not only are Pa-Dong people treated as migrants, their humanity is devalued and they are confined in a "human zoo". A documentary of the same title, "Human Zoo", produced by Imagine Mekong, reflects the different perceptions of the brass rings worn on the necks of Pa-Dong women. While Pa-Dong people regard the brass rings in cultural association with the sacred swan, concerned authorities consider them as "strange objects", hence the arrangement of their village as a tourist attraction.

A study by Erving Goffman (1963), a thinker with extensive work on stigma and the stigma theory, clearly stresses that social stigma or recognition of a behavior as misconduct will brand those who have committed it with a sin or disgrace. Social norms of morality and accepted behaviors have become the standard that prescribes "right or wrong" and "decent or indecent". If someone commits something that is regarded as wrong or indecent by the society, they will immediately be considered as deviant. These negative and positive definitions and values derive from people in the society and are passed on through social mechanism and structure. Through a continuous transitional process, these socially constructed "categorizing tools" have become social norms that eventually transform into a "social identity" that binds those living in a society together under a common value (Erving Goffman, 1963:2).

Similarly, this study attempts to provide an understanding of stigma and discrimination from a holistic perspective between relevant theologies and studies. The definitions used herein are based on the questionnaire User Guide which explains stigma in two different ways.

First, stigma is something that represents shame or disgrace. This definition derives from an act of labeling or marking in the old days that was done to someone deemed as "immoral or defiled" by the society, or to those found guilty of any misconduct and should therefore be dissociated with by others. Normally, stigma is a process of devaluation. If someone is deemed as "flawed" by others, they are defamed, disgraced or devalued in others' eyes.

For HIV-positive people, stigma is an impetus for other social bias including prejudice against gender, sexuality and race. For instance, stigma against HIV-positive people is usually associated with AIDS or immoral behaviors, and restricted to specific groups of people such as sex workers, drug users, homosexuals and transgender people. Because of relationship, not only does stigma impact HIV-positive people themselves, it also affect those associated with them including their sex partners, spouses, children and other family members.

Second, internal stigma or self stigma (self-granted stigma or self-stigmatization) are used to explain feelings of HIV-positive people toward themselves especially when they feel embarrassed of their positive status. This can lead to low self-esteem, self-devaluation and depression. This internal stigma can also lead to isolation from society, dissociation with others, or refusal to access healthcare services for fear of disclosure and the consequent discrimination based on their HIV status.

HIV/AIDS, Stigma and Discrimination in Thai Society

Why are HIV-positive people stigmatized against?

There are a number of responses to this question. Some samples are as follows.

1. People associate HIV infection with behaviors of populations at risk including homosexuals, drug users, sex workers or anyone with promiscuous behaviors. Is it true, however, that stigma hurts the heart more than the body? Campaign slogans that label infected people as the bad people in the society are a case in point. For example, "promiscuity leads all to AIDS", "promiscuity equals AIDS & death", or "no promiscuity, no needles, no AIDS".
2. HIV/AIDS is a threat to life and those around anyone infected.
3. Most positive people contract HIV through sexual activities while sexually transmitted diseases are associated with the prejudice that sex is "immoral". Therefore, anyone associated with sex (beyond socially accepted moral standards) is regarded as "immoral".
4. Disseminated information on the spread of HIV and its transmission is not clear, correct or well thought through.
5. HIV infection is used to refer to one's irresponsibility.
6. Religions and beliefs lead people to the understanding that HIV is a punishment someone with misconduct deserves.

Nonetheless, one should further consider the link between stigma and the awareness/unawareness of HIV/AIDS. In other words, stigma against HIV/AIDS can depend on perception. For example, it is sometimes treated as an issue for experts. Since the start of the epidemic in Thailand in 1984, AIDS was classified as a "communicable disease" that must be contained. Therefore, HIV/AIDS was confined within the realm of epidemiology only.

The document entitled "Echoing Voices From Afar on HIV/AIDS", which reported on the impact and the outcome of the implementation of the economic, social and cultural development plan in the Northeast of Thailand, presents critical information on the link between perception and HIV/AIDS and its consequence at implementation level where the response to HIV/AIDS centered around prevention. In 1992, the 100% condom project was initiated and more than 60,000,000 condoms were distributed. In the following year, Thailand saw a worsening spread of HIV, prompting the Ministry of Public Health to bring the issue to the Office of the Prime Minister. As a result, HIV/AIDS intervention budget increased from 20 to 44 million US dollars (based on the Economic, Social and Cultural Rights Development Plan, 2008).

The perception that AIDS is only a communicable disease results in the confinement of HIV/AIDS in epidemiology. Such confinement restricts perception on HIV/AIDS in other dimensions such as the link between HIV/AIDS and stigma and discrimination despite the magnitude of its seriousness in the society. As a result, stigma and discrimination continues to persist.

From the perspective of policymakers, the perception that AIDS is a communicable disease has been firmly established. At the 9th National AIDS Conference on 7-9 July 2003 at Impact Convention Center, Muang Thong Tani, Nonthaburi, an address by the then Public Health Minister H.E. Sudarat Kayurapan can exemplify this. The address says that HIV/AIDS response must:

1. Improve the knowledge, attitudes and behaviors necessary for the prevention of HIV/AIDS in a way that can best reduce risk behaviors, promote access to services to prevent transmission and access to condom for those practicing sexual risk behaviors.
2. Better study the impact of HIV/AIDS on individuals and their family and recommend appropriate solutions thereof so as to encourage those infected and affected to access quality and comprehensive services.

3. Employ appropriate strategies for intervention and solutions to AIDS related issues. These have resulted in the initiation of the national AIDS committee that is chaired by the highest administration authority/leader. This committee establishes policies for HIV prevention and solution. However, improvement is needed in partnership building for a concerted effort to tackle HIV/AIDS issues more effectively and in a timely manner, and that any strategy or approach employed must respond to the needs and the plight of the people at all levels. To pursue this under a resource-limited condition, those involved must consult a holistic approach to problem analysis and translate that approach into an appropriate problem-solving strategy with strong support from networks.[2]

It can be seen from this address that government's policy to tackle HIV/AIDS issues is to reduce risk behaviors in order to prevent transmission. This is an example of a confined perception under epidemiology.

From Stigma to Discrimination

Stigma also relates to discrimination. Because prejudice against and the devaluation of those stigmatized against make them different from others, they are treated differently or unequally. Such treatment is usually negative.

Discrimination means treatment of others with prejudice or bias in an unfair or unequal manner. This usually happens to those discriminated on the basis of how much they have or to what particular group they belong. In most cases, it is deemed as a result of stigmatization. In other words, enacted stigma results in discrimination.

At the same time, discrimination may also mean an act incited by stigma against a particular person or an exception thereof. For example, discrimination against HIV-positive people happens when someone is treated differently from others (or that they are put at a disadvantage) because their HIV status is known to or suspected by others, or because of their relationship with an infected person (i.e. spouses or family members). Discrimination also happens at various levels, either in a family or a community. For example, when others in the family shun their HIV-positive member, avoid sharing kitchen utensils, or refuse such member acceptance into or association with the group.

Discrimination also prevails in public institutions or environments. HIV-positive people may be separated from other patients in a hospital or denied access to healthcare services or health security merely on the basis of their HIV status. Some supervisors disrespect the rights of positive people or disclose their positive subordinates' status without their consent. Some positive children may be prohibited from going to school.

Furthermore, discrimination exists at the national level through the passing of laws or policies that allow or foster lawful discrimination. For instance, restriction of entry into a country based on HIV status, prohibition of certain occupations or compulsory HIV testing for certain people. In any case, discrimination against HIV-positive people or those suspected of having AIDS is violation of human rights, and is a problem that requires the national legal system to solve.

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[2] http://www.aidsthai.org/main.php?filename=policy_aidsinter

In sum, the journey of stigma takes off from the "culture" as a structural determiner of a set of values and norms held by people in the same society through language, manifestation or convention determined by that society. In case of HIV, stigma prescribes a set of values for positive people in conjunction with a set of values in sex and sexuality, which in turn leads to judgment of such values, labeling or stigmatization. Eventually, it results in discrimination which directly links to human rights violation and deprivation.

HIV/AIDS and Rights in the Thai Society

A paradigm shift that connected HIV/AIDS with human rights occurred in 2003 when regulations by the government and relevant authorities started to address rights issues. Such transition began with an attempt to include HIV/AIDS into the health security. Then, in October 2005, the government approved the inclusion of treatment of HIV/AIDS patients with anti-retroviral drugs into the National Health Scheme (Economic, Social and Cultural Development Plan, 2008).

The said policies reflects an extent of success in eradicating an encoded recognition that people infected with HIV are terminally ill, incurable, or that they deserve death because they themselves are promiscuous, immoral and the cause for their own HIV infection.

The notable movement for rights issues in the past decade in Thailand has been an attempt to regard sexual rights as social and cultural agenda. Groups advocating for sexual rights issues, sexual identity and sexuality started to establish themselves. Anjaree is a group for females who have sex with females while M-plus and Rainbow Sky are for men who have sex with men and transgender people. MPower Foundation focuses on promoting the ability to live with pride and dignity for female sex workers and giving them back the humanity that the "good women" norm and Thai women convention have taken away from them and instead replaced with stigmatization that what they do for a living is sinful, immoral and defiled. These groups are an example of a paradigm shift for HIV/AIDS to a new authoritative relationship management approach in the Thai society.

Nonetheless, a report on human rights in relation to HIV/AIDS in Thailand by the Foundation for AIDS Rights in 2008 (Foundation for AIDS Rights, 2008) reveals that human rights violations continue to prevail in the Thai society, chiefly as a result of prejudice against race, religion and sex. In the case of the 3 Deep South provinces, the government neglected to solve the problem despite its seriousness and rampant political instability and failed to come up with clear measures or policies to demonstrate care for those residents in the area as Thai citizens. On the other hand, bias based on ethnicity against migrant labors from borders along Myanmar and Laos also exists and result in these migrants being treated differently. The fact that they are identified as "migrant workers" creates complications in integrating them into the Thai cultural structure. Consequently, human trade on them thrives on.

The incident of the 54 Burmese migrant workers suffocated and crammed to death in a refrigeration truck from Ranong to Phang Gna and Phuket in April 2008 shows that human trafficking is not a small business done sporadically and reflects the fact that human rights are a fundamental issue that deserves more attention should the society see value and dignity in every human being.

A study on Human Rights and Health Rights (Surasom Kritsanajuta et al, 2007) examined the conception in and challenges to rights and human rights issues in the

Thai society. Findings from the study include health rights violations in different dimensions, i.e. migrant workers spraying pesticides in orange farms without proper protection thereby burdening health risks instead of the Thai Yai labors; HIV-positive people being attached to the stereotype that HIV/AIDS is a result of promiscuity or having unscrupulous sexual behaviors which then lead them to infection; or, transvestites who are branded for having conflicting sexuality from their biological sex based on cultural perception. Furthermore, labors in factories are sometimes regarded as "human resource" whose value is determined by their skills and competencies. If they fail to fulfill job expectations or make mistakes, they are devaluated and deemed as incapable. The humanity in them goes unnoticed.

The same study suggested that the society needed an effort for a paradigm shift that rights are not just something the government grants to its people by legislation or as universal social standards. But because rights violation is very complicated, legal measures are only an approach to help ensure rights in the society. Therefore, the said paradigm shift should focus on linking "rights" to "humanity" in order to ascertain an authoritative relationship management approach that doesn't devaluate, stigmatize or discriminate against HIV-positive people. On the other hand, positive people themselves must also attempt to establish their own health rights.

This study was an attempt to translate awareness into practice. It was hoped that this process of mutual learning and exchange among the study team would increase the understanding about the extent and forms of stigma and discrimination against HIV-positive people in Thailand. Moreover, it was expected that the study would be used as a tool in catalyzing change more widely and to inform the strategy for pushing forward the agenda by all involved, especially in the strengthening of the positive networks and human rights advocacy.

Chapter 2

Thinking, Doing and Learning Together

From positive peers to researchers

From common plight to coming together

People diagnosed with HIV take different options after learning of their status. Some choose to keep the matter to themselves and end up with stress while others consult with whom they trust. Certain people move to another place or think of committing suicide. But amid this deadlock between living on and stability in life or the anxiety from the thought of living with the disease, some people stand up on their own and for themselves. They seek treatment, herbal remedies, drugs sold over the counter, or superstitious cures from monks or even celestial beings, etc.

This effort in trying to find a "way out" bridges the gap and brings people having "the same problem" or "sharing the same plight" together. They help alleviate the suffer for each other and organize themselves more concretely in both cities and rural areas.

This process of coming together is what HIV-positive people use in their fight against HIV/AIDS, labeling, stigma, discrimination and exclusion. They group and network to respond to and challenge all the problems and crises they face.

A study by Tawat Maneepong et al (1999) on the formation of positive groups found that such development can evolve in different ways. For example, positive people who meet in a hospital or alternate healthcare center may get to know each other, share their experiences and create a self-help group among peers. Other groups may get support from an organization and meet at any arranged occasions.

After concerned authorities recognized that coming together was an important mechanism in healing HIV-infected people and as a result of the International Conference on HIV/AIDS in Asia Pacific (ICAAP) in Chiangmai in 1995, this grouping process was taken on systematically. The momentum reflected the strong response to HIV/AIDS in Thailand and the grouping process brought about skill development and adaptation by positive people. Establishment of self-help groups, the promotion of condom use, among other things, were cited as the success of a participatory approach to solving HIV/AIDS problems in the Thai society.

Later, the government, the Thai NGO Coalition on AIDS, university research teams, etc., came into the scene and provided support to the group and the network which consequently formalized themselves as the Thai Network of People Living with HIV/AIDS (TNP+). For over 10 years now, TNP+ consists of board members, all of whom are positive, and receives collaboration from governmental organizations and vice versa.

The three birds of rights movement

This study was initiated and implemented by TNP+ in conjunction with the Foundation for AIDS Rights which has been working on HIV/AIDS rights issues in Thailand for over 10 years.

This project had 3 important objectives, hence its title by the study team as the **"three birds"**.

The first objective or bird was to **"build capacity"** by training and providing opportunity for positive people selected by their group or network to serve as researchers. Through this process, they had a chance to understand the concept and the implementation in relation to rights and human rights issues.

The second bird was to **"develop index"**. Though this study may not produce the index of stigma and discrimination representative of the entire positive population in Thailand, it formed the basis for the understanding of the extent, forms, factors, conditions and diversity relevant to stigma and discrimination in the society.

The third bird was to **"build mechanism for rights movement"**. This was an expectation that the peer members of the study team would enhance their capacity to become peer leaders in driving rights issues for HIV-positive people in Thailand by working in partnership with relevant authorities and other organizations rather than waiting for help from them. This would strengthen positive networks so that they could represent and provide support to their positive fellows across the country. This three birds strategy employed a "research process" in realizing all the objectives through one activity. That is, positive people could change their perception by joining the study team, they better understood stigma and discrimination issues and a mechanism driving rights issues forward was established.

The following explains how the process transformed positive people into researchers.

Building capacity: from positive people to researchers

For the limited period of time to conduct the study, the most important question for the team was how to organize the knowhow and integrate the experiences in rights issues, stigma and discrimination of the 13 members of the team so that they could think systematically. In addition, enhancing skills, understanding characteristics of researchers, constructing questions, and collection of information were needed. Thus, to realize all these, a "workshop process" was suitable for the limited time available.

Two workshops were then held. The first workshop was organized on 17-18 March 2009 at Baan Sabai, Bangkok, and focused on building the capacity of positive people to advocate for human rights through developing index of stigma and discrimination against HIV-positive people. This was the first time the study team members met. Some members knew each other before yet had never talked or worked together, therefore an ice-breaking activity was essential. Then, the team together came up with the "rights agenda" which incorporated the varying experiences of all the members into the study framework on rights and health.

Initially, the team identified the scope within which rights were to be discussed by developing a conceptual framework. They based the framework on the study of Surasom Kritsanajuta et al (2007) which explained the following 6 fundamental concepts on rights.

1. **Humanity** emphasizes on how to see the world with humans as the center, or humanism. This concept is an important tool which humans use to deliberate themselves from control over their life as a result of beliefs in god and religion. Humanity means respect for diversity in humans and the society. It also stresses that the realization of human value of the individual has a meaning for every phenomenon.

2. **Liberal** respects the freedom of humans, confides in the decision-making by an individual and doesn't deny the government but intrusion by the authority. In other words, it doesn't deny the government or favors autonomous existence like the anarchists but endorses the rights of an individual as a citizen who deserves protection by the government. Liberal was influential in the movement of "civil rights".

3. **Universality** treats every human equally. It recognizes the needs for happiness, food and a place to live and that these needs are basic, natural, intrinsic and cannot be taken away. This concept usually appears in declarations on fundamental rights because it is believed that it can be applied to everyone, everywhere and at all times regardless of sex, age, skin color, ethnicity, nationality, etc.

4. **Egalitarian** underlines the importance of what humans deserve but not necessarily equal access to it. This is from the perspective that absence of equality leads to inequality. Egalitarian stresses the rights of being human. Therefore, as citizens, people deserve the respect, care, protection equally by their government. On the contrary, they deserve remedy if their rights are violated or restricted for every human has dignity. Although humans are diverse, everyone is born empty-handed and thus deserves the same respect. A word that can closely match egalitarian in meaning is impartiality, meaning everyone is entitled to their rights and satisfied in exercising them. On the other hand, if someone who is inferior is deprived of their rights without reasonable ground, that is discrimination.

5. **Rationality** believes that "humans are rational animals". This was influenced by the age of enlightenment when there was an attempt to separate humans from animals and at the same time to deliberate them from the mastery of god. However, rights are not about reasons only for humans have emotions and feelings which can be complex. Therefore, rights denote that humans are born equal, on the bases of reasons and feelings.

6. **Utilitarian** links the individual and the government. On one hand, it highlights the humanity of a person, allows an individual to be what he wants to be, while at the same time touches upon the rights of the citizens that the government must protect and seeks to distribute happiness and benefits for the majority. This is based on the concept that the state is the provider of benefits to its people. It seems that this concept overlaps between individualism/maintenance of individual's rights and government's requirements. Nonetheless, the society must agree how to maintain balance and define a scope and criteria to manage between personal interest and that of the majority.

Though understanding these fundamental concepts on human rights thoroughly was not easy to achieve within a limited time, it was an important initial lesson for the study team as it provided an opportunity to gather and connect this research experience for increasing knowledge and laying groundwork for the advocacy work of TNP+.

Not only could the acquired understanding of these concepts be used in their role as the study team, the process after the study was also beneficial. Particularly, the interpretation of violations or demand for the rights as a citizen rather than an individual, and the fact that government was not a mechanism or institution isolated

from the society, led to the understanding that these interrelated components were a set of cultural definition.

Thus, understanding rights must employ a holistic approach and from different aspects and levels of social relationships, from an individual to a global scale. In other words, to understand these issues, one must understand the "rights cycle" (Surasom et al, cited : 95). This conception is adapted from that of Dr. Weera Somboon as earlier presented.

Diagram 1: The Rights Cycle

(1) Learning social rights		
(2) Conceptualize social rights	Rights Cycle	(3) Impetuses (law, social norms, etc.)
(4) Learn / foster learning		(5) Channel of rights
(6) Space and activity on rights		
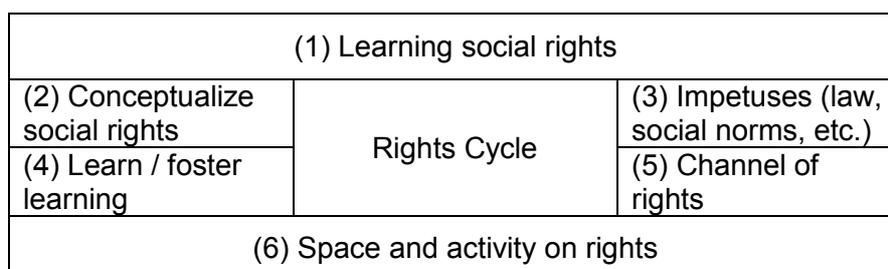
This rights cycle represents the interconnection among people (individuals), government (institution) and social mechanism (law) which influence one another, be it fostering the learning or understanding the various concepts. This study created the conceptualization and the awareness of rights. The study team members had the opportunity to understand stigma, discrimination and violations from phenomena experienced by their fellow positive people. This understanding was not based on reasons only but also the feelings and emotions of HIV-positive people as the victims of such phenomena. In the future, findings from this study can be shared with the society in order to create rights channels to accommodate the various and complicated problems or impact suffered by positive people. These channels can also accommodate solutions or remedies for those affected or suffered from violations. Lastly, it was hoped that this study would lead to the development of and changes to social and cultural norms that deliberate those who are oppressed and violated.

Questionnaire and Developing the Index

Besides learning and understanding the principles about rights and human rights, positive peer leaders integrated themselves further by learning and developing the tools together. In this process, what also happened was that they came to understand the study question and the goal of the project through a tool called "questionnaire on index of stigma and discrimination against HIV-positive people"[1] by an initiation and development collaborated by 4 organizations; namely, the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The study team meticulously studied the questionnaire and its manual, and also adjusted certain questions for conformity to social and cultural contexts of Thailand.

The questionnaire consists of 3 key sections. The first section aims to gather general information about the respondent (and family). The second section focuses on the

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[1] See appendix.

experience of the respondent regarding social stigma, self/internal stigma and protection of HIV-positive people through legislation, policy, enforcement and any changes taken place in the last 12 months (from the date of interview). The third section zooms in on anecdotes about stigma and/or discrimination against HIV in the last 12 months, particularly in the cases of blood testing, disclosure and preparation for treatment upon signs of symptoms. The study team members read, conceptualized, interpreted and asked questions for mutual clarification. They then tried the questionnaire in their respective assigned areas.

Researcher skills enhancement process

The second workshop took place on 1-2 April 2009 at Baan Sabai in Bangkok. This consequent session focused on translating the experiences from the trial into improving both the questionnaire and the questioning method, in addition to understanding the feelings and emotions of the respondents.

Over the 20 days of data collection trial, not only did the study team members improve their communication process and skills, they also found that questions constructing was critical and that the positive peer leaders must act as both the "learner" and the "knowledge builder" in the process. Therefore, the workshop 1) reflected on what happened during the data collection trial, and 2) further enhanced the research skills through coaching by pairing up and taking turns in providing feedback and inputs.

1) Reflecting what happened during the data collection trial

Three main issues were identified. First, there were too many questions and some were probing too deeply, resulting in the discontinuation of questioning and the inability to clearly understand the questions being asked. Second, there was internal discomfort being "researchers for the first time". Some team members worried that some questions could be taken as intrusive but the respondents would have to answer anyway only to be considerate. The third issue was about dealing with feelings and emotional outbursts of the respondents, causing them to get emotional and cry along with the respondents especially in cases of discrimination coupled with misfortunes such as being disabled, infected and deserted.

These issues reflected two aspects of having researchers who were the "insiders". On one hand, it was a complementary factor for they understood the pain positive people do not want to talk about and are cautious to not trespass into that territory. This is helpful in a research on such sensitive issue as "sharing the same fate" gains the respondents' trust and enable them to open up. On the other hand, it creates internal worry for fear of triggering the pain suffered by the respondents.

2) Enhancing research skills through coaching

Coaching was an important in the learning and grooming of the selected study team members. It was convenient in simulating the situation and easy for the members' learning by taking turns playing the roles of the interviewer and the respondent. The coach as the respondent can feedback on the questioning, tone of voice, use of language, gestures, eye contact, etc.

Below are examples of feedback from the coaches.

"A bit tense when asking the questions and discontinuation in questioning. Therefore, improvement is needed in the clear understanding of the questions being asked. Nonetheless, it was good to be attentive to the respondent's general feelings by periodically checking if the respondent understands, how the person feels, if the person needs to go to the toilet or is thirsty." (02)

"Self-introduction was clear yet a bit tense. Missed certain questions and further probed into those that require only yes or no answers, thereby delaying the process." (03)

"No weakness. Excellent act. Good self-introduction followed by objectives and length of time needed for the session. Being friendly, right to the point and was good to regularly repeat the questions." (04)

"Good introduction but slow in getting to the questions. However, the respondent understood the questions well as questions were repeated. Nonetheless, thorough understanding of the questions was needed." (05)

"Employed personal technique by giving the blank questionnaire to the respondent while conducting the session and was friendly. Repeated the questions when the respondent didn't understand. Needed to understand the questionnaire more clearly, in addition to the objectives of data collection. (Because of) Friendship resulted in asking too much and causing discontinuation in questions regarding transmission from mother to child, plan to have children, regimen taken, definitions, etc." (06)

"Information about the project was unclear, especially on the rationale. Forgot to make sure about the availability of the time the respondent had. Questions asked were clear, repeated as necessary and well connected. Friendly. Able to pinpoint the main issues to guide the respondent." (07)

"Did introduction and explained objectives. Spoke articulately, repeated questions, had sense of humor and able to get back on track (picked up lessons and points from partner). Spoke fast and used local accent." (08)

"Good self-introduction and could understand questions clearly. Should accommodate conditions of and how the respondent would like to answer." (09)

"Attempted to facilitate smooth questioning and comfort in responding by the respondent, eased worry and stress and stimulated the conversation by providing information. Read the questions without using spoken language, i.e. saying "slash" for "/". Did not recheck conflicting information, i.e. the number of family members versus the fact that the respondent lived alone as provided on page 14. Did not provide clear and sufficient information, i.e. if transmission can happen by giving oral sex to partner." (10)

"Good self-introduction and answered the respondent's questions clearly. Facilitated flow of conversation, gave opportunity for respondent to question back and used simple language, i.e. if ever been gossiped by others or if ever thought of being gossiped by others. Gave examples, asked additional questions, but sometimes missed relevant questions." (11)
"Good effort in understanding the questions to ask. Used personal experiences for respondent's easy understanding. A bit tense but should be better in actual situation. Interviewer and respondent didn't look at each other,

resulting in no eye contact which could cause respondent to think interviewer didn't care. Objectives were unclear – need to revise. Sometimes interpretation of the questions was incomplete, i.e. if the answers to no. 1-7 were No then question 8 was to be skipped. So, more attention to the details of the questions was needed. Trust-building was necessary in order to ensure a relaxed atmosphere." (12)

"Not enough information on the project. Asked general health questions and well-being. Clear explanations with good tone of voice. Repeated questions as needed. Some light talk to create friendly atmosphere. Forgot the question had been asked when the respondent got back on track after getting carried away." (13)

It was intended that all the feedbacks from the 13 coaches were to be presented herein to illustrate the interactions during the session and what the respondent recognized the interviewer did well. On the other hand, the respondent as the coach could identify the best question asked when the interviewer didn't do well. This was an automatic learning process suitable for a short yet complex training that could readily be applied for all the field researchers.

In the feedback from coach 08, the coach's partner played the respondent's role, had the chance to listen to feedback first and could do well after switching the role to play the interviewer. Similarly, others could also feedback their partners after switching. Some of the feedbacks included not looking at each other, lack of eye contact, use of formal written language, respondent didn't have the questionnaire in hand, making it difficult to answer long questions, pressing for a quick answer without giving enough time for the respondent to think, or the interviewer's missing the point of the question.

Some good recommendations came out of this coaching process. For example, sometimes the respondent's use of words, tone of voice or gestures changed. Therefore, the interviewer must be quick enough to notice these changes. Also, it was crucial for the interviewer to understand the questions clearly, their meanings and connection. So, the interviewer should be well-versed and knowledgeable in different areas and subjects.

The points identified and the atmosphere explained above proved the appropriateness of the process/strategy employed. It helped enhance the skills in constructing questions, synthesizing and analyzing the responses in real time, including dealing with situations beyond the interviewer's control such as getting emotional about the issues faced by the respondent. These were not easy for "amateur researchers".

From friends of the positives to information providers: sensitive research for lives

When the day these new researchers had to go on the field came, they ensured their readiness in addition to understanding of the tool being used and their role. More importantly, this research was instrumental in raising the awareness that many positive people didn't understand the complicated stigma and discrimination process, or that did they know about their rights and the many organizations working on and advocating for these issues in order to improve the rights of positive people.

The interview conducted by the 13 researchers in this project reflected their personal experiences in obstacles faced in the process. Some of them are shared below.

The meeting place: an important factor

As earlier mentioned, selecting respondents who were the target group to answer the questions could not be identified, apportioned or randomly selected in advance. The only expectation was that there would be "friends" (herein referred to as the research subjects) who would be willing to share their experiences. Therefore, a meeting place was important while other factors must be considered. These included options if the target friends were not open about HIV status within their community, or where they worked to minimize the burden of traveling.

Below is a list of some places chosen by the researchers for different circumstances.

No.	Place	Condition/Reason
1	Friend's house	Chosen by and convenient for the friend. Under the tree in front of the house if inconvenient inside the house for fear of some questions that could not be known by the family.
2	Peer leader's house	Friend's house not convenient and far enough from there. Safe.
3	Researcher's house	Chosen by friend. Other places not suitable. Friend's house not convenient. Friend's considerateness. Family not known of HIV status.
4	Friend's office	Convenient for friend.
5	Club/group's office	An office room in a hospital or a rented house.
6	Network office	Suitable and timing allows.
7	Public park	Chosen by friend on a meeting day of support group at hospital. Few people on any workday. Sitting on the grass comfortable.
8	Hospital	Support group meeting place, a lawn on the compound.
9	Temple	Friend is ordained. House not convenient.
10	Hotel, training/meeting venue	Convenient as friend is there but has to wait till after the activity.
11	Shopping malls	Convenient for friend. Usually has a quite corner.
12	Nursing home	Friend's residence together with other positive fellows.
13	Shelter home (in cases of rejection from family/no one available to take care of at home/unemployed/ not able to afford rent	Convenient as all residents are positive.
14	Beach	Convenient. Friend works there.
15	Hut on rice field	Not convenient at home. Such a hut at a different village is safe. No one can see. Cannot discuss sex issues in the house (female friend) though HIV issues are okay.
16	Church	Friend is religious leader. Convenient.
17	On a boat	Job allows and convenient.
18	Pier	Friend's work.

| 19 | Mango garden | Not convenient at home. Many family members. |

Thus, even a meeting place was crucial and could not be overlooked. Unlike other matters for which any place would be convenient, this was an important factor for discussing such sensitive issues as HIV/AIDS as they were not to be known by others and the society. Furthermore, a good meeting place allowed the researchers to see the other side of the life of a positive friend that could be filled with emotions and feelings during the crisis.

Evaluating the opportunity to reach the "friends"

Reaching a friend for data collection may vary as follows

1) The researcher must identify a known friend who has really been stigmatized or discriminated against and is someone on the prospect list. Another possibility is to introduce the project to friends who are females having sex with females, men who have sex with men, sex workers or the general public and ask them to locate the occurrences of stigma. Some friends may offer the help from their own experience, and after verification, could become the respondents. Support group members who work as sex workers are a case in point. If they work at night and have to be with their partners during the day, they can be taken "off" during work hours for the interview on condition that their time will be dedicated for such purpose only without having to disturb their work.

2) Networks or peer leaders can connect the researchers to the target friends who can then pass on the information to their peers who may be willing to share their stories. This can be done after a group activity and the friends can choose the meeting place, whether it be a house or a hospital. A researcher cited a situation where 5 out of 20 friends didn't feel comfortable to meet at their houses. One of the five was a transgender person, infected, physically hurt by the father who could chase the researcher out of the house. Under such a circumstance, it would be better for the friend to choose the meeting place.

   Another researcher shared that contact was made to a positive network and introduction was given. After one week, the researcher followed up to see if there were any prospective cases for the project but was told there were very few. After an actual field interview and having found some problems, the researcher questioned the answer whether there were really few cases or people just didn't see them. A few specific cases had an overlapping status and complicated experience. A transgender person being rejected a loan application on the basis of her HIV status disclosure was a case in point. She faced double violations from her gender and HIV status.

3) Some researchers use their own work as an opportunity to reach the target friends. For example, some worked as DJ's, introduced the project through the radio program and received very good response. Some prospective friends called in and made an appointment for an interview. This was an example of a far-reaching method.

Availability and complication issues of the friends

Mostly, researchers could achieve an average of two interviews per day. The delay and tiredness resulted from the effort put into the clarification of the questions. Sometimes being direct was necessary or such indirectness could shy the respondents away from answering. Therefore, it should be agreed beforehand that the interview would be straightforward or the researchers would not be able to expect straightforwardness of the responses. For example, some people do not talk about their own sexuality, family situation or past stigma and discrimination experiences. As a result, the researchers would not be able to fill in the answers correctly.

Multi-dimensional obstacles

The research team faced multiple challenges in the interview process.

Transportation: The distance for a respondent to travel to the meeting place could be far and required a long time for travel. Some areas were too far for public transportation to reach be available. A few respondents may have to leave their houses at 1 am and reach home again at 11 pm. Some got caught or stuck in the rain, or risked different sorts of danger. Sometimes a motorbike taxi was the only means of transportation.

Language and Communication: This obstacle prevailed at two levels. First, the language used in the questionnaire was too difficult to understand and different from the everyday language used by both the respondents and the researchers. Second, there needed to be translation for more than one language for migrant workers, causing further delay and misunderstanding on the questions.

Short data collection timeframe: The researchers spent a lot of time in traveling in order to complete the work in time. Some prospective respondents didn't show up.

Distractions during the conversation: During a conversation, a cousin of the friend's walked in and said "where did you get this vicious disease?," thereby disturbing the conversation. Sometimes a researcher could be seen as a stranger in the neighborhood of the meeting place, drawing attention for some uninvited neighbors to join the conversation.

Special conditions: Some friends worked as sex workers and had to work at night. Therefore, they had to be paid to go out with the researchers so that their working hours were not disturbed. Sometimes a friend felt pressured during the conversation and the researcher had to stop for fear of jogging the friend's ordeal. Nonetheless, some respondents had gotten over their bitter experiences.

"Weaving" the researchers' experiences

Field experience as researchers brought about a number of changes. One significant lesson learned was perception of the same thing from the researcher's "perspective" using a "new" tool. They found that things people are familiar with, i.e. HIV/AIDS issues both for those affected by it and the society at large, can be more complex and severe than they may think. Similarly, in their role as the positive peer leaders, they came to realize how much the work of networks and national stakeholders means to the confrontation with the challenges faced by HIV-positive people. Some interview excerpts of the researchers on this study exemplify this.

A research study enables the realization of the problem from a broader and exhaustive dimension. That is, researchers can analyze HIV/AIDS problems from both economic and social perspectives, and as a root cause at individual level.

"We thought our experiences were horrible but those of our friends were worse. We couldn't help crying. There are many things that we don't know."

"We learned that some people stood up and fought whereas others accepted it and stigmatized against themselves and felt devaluated. Some let others oppress them. For some, the interview reminded them of the wounds they had while others never had someone to listen to or to see value in them. For example, respondents at Poo Saang didn't want referral services but only needed someone to listen to them."

Research is a mirror reflecting the work in the past 20 years. Phenomena experienced in the field presented flashbacks of and helped to review the work and its effectiveness in the past 20 years. On one hand, the experience, the skills and the understanding of the rights of HIV-positive issues have increased continuously. On the other hand, stigma has continued to prevail and this research process has enabled a deeper understanding of the issues and the consequent sufferings from it.

"Being a field researcher provided me with an opportunity to meet with friends of diverse backgrounds. Most of them told their stories while crying. Female sex workers were more emotionally stable while many gays and lesbians had a new life with partners or husbands. We learned about these different experiences and found different forms of stigma and discrimination. Internal stigma prevailed in most cases. We learned of friends' stories which in turn caused self stigma for ourselves."

"This research experience enabled us to see different ways of thinking. We came to realize that a particular community cannot solve the problem by itself but needs collaboration from multilateral partners. Our strategy is to help reinforce their strengths and thereby improve ourselves."

"We learned about the different ways our friends dealt with the problem. Those in the early days of the epidemic had done a lot of work, resulting in minimized impact for those recently infected. This was a proof that without the efforts by the positive people in the past the status quo then would have not been better. It also emphasized that if we had not been part of the solution, our problem would have persisted."

"Many people we interviewed responded that pregnancy is not just about having a baby but it relates to the spouse, family and community. The amount of information we received revealed that the community didn't agree with positive people's pregnancy. This made us think whether the counseling we have had over the years has been effective enough. A friend we interviewed had an unintended pregnancy and was continuously verbally assaulted by a peer leader at the hospital even until when she was about to deliver the baby. Therefore, if the concerned community failed to see it, the problem would not be solved and such insulting remarks as 'you must go for an abortion' or 'you must undergo sterilization' would persist."

"The hospital staff disclosed our information in public, gave advice and insulted on how we take our drugs in front of others and the doctor allowed his wife to call our names. Even the OPD cards were not properly kept or covered. These violations seem to be so systematic."

"The doctor was discriminatory. A friend had knee pain and went to the hospital. A trainee medical student who came with a doctor was about to do blood draw from the knee. The doctor said the medical student was not allowed because the patient was

HIV positive and people's faces turned to that friend. Then, the doctor drew blood from the knee and put it on a splint but didn't tell the friend what it was for. He said it was all because of karma. Later on, this friend went back to the hospital because of shoulder pain. Initially, she was supposed to undergo an operation but after going through the OPD the doctor refused to do the operation and told her to go home."

Improved attitudes and knowledge at individual level. Field experience helped increase understanding in different areas including sex, gender, sexuality and legal loopholes.

"When first approached, I was interested to be part of this research. After accepting it, I thought this was difficult and only researchers could do it. I also thought the questionnaire I saw at the training was difficult. However, the actual implementation changed my perspective. Before, I believed in monogamy and would not do anything that's unacceptable by the society in order to avoid rejection and being seen as deviant.

Through this research process, I learned about other friends' lives and came to understand that different backgrounds resulted in different perceptions. For instance, in the case of sexuality, I used to think transvestites were emotional and dramatic, sometimes uncontrollable. If I were to choose to work or live with someone, they would not be my choice. However, this research process made me realize I should not violate others that way. I became more cautious about what I say and realized that transvestites are very sincere."

"First I was not sure if I could do it and that only educated people can. But because I also have the same problem, I could see and understand the issues. I understand my friends, feel how they feel and sometimes can't help crying with them. As a result, I though since it was also my problem so I should be able to do it and be part of the solution."

"I personally changed. I did not accept certain people before but now I do. I used to shun and stay away from transvestites but now I see them as the same human beings. I can accept the way I am and the way others are. This hands-on and experiential process really changed the way we think."

"Legal loopholes were exploited to discriminate against HIV-positive people. The 24 friends I talked to were not allowed to have life insurance policy despite the fact that there's no clear-cut legislation on it."

"Some of the friends who were violated their rights did not know where to turn to. If there were, they could not be assured of the assistance that would be offered. We saw the disadvantages our friends faced, their total surrender to the stigma and discrimination, and their submission instead of reaction. Villagers tend to be at a disadvantage when it comes to negotiation of rights and have fewer channels to demand their rights. The community, peer leaders and villagers do not know how the law works."

"I used to stigmatize against others. This field experience enabled me to see the picture and understand the levels of stigma and discrimination. I realized I had stigmatized against others unintentionally."

"I learned that we're all the same. I saw different aspects of couple life, be it between heterosexuals, homosexuals, male-transvestite, etc. Each couple has its own challenges in the eyes of the society and that's something you can't read in the books. We also came to understand people of other nationalities more, including the questions of why we were born into this world or why some people became

victimized. One of the questions I used was to classify people on the basis on citizenship. If someone is not Thai, then they are not equal human?"

"We learned about stigma and discrimination but how can others learn about this, too?"

The excerpts above were critical in this research project as they echo the potential that we can achieve the goal of "capacity building" so as to enable people to see problems from broader perspectives and at a new depth. While on the field that was filled with the challenges of others, the researchers didn't see only an individual's problems but also a reflection of the group or the network's effort whether it has been effective in its implementation, advocacy or problem-solving. Last but not least, the researchers themselves experienced some personal changes. They had a different perception of sexuality, understood prejudice on the bases of sex, ethnicity, social status, etc. This "knowledge capital" was crucial in expanding the work and achieving results in the future.

Value beyond a research paper

Based on the framework of this research project, this chapter resembles the second bird which aims to develop the "people" so that they can serve as the driving force in advocating for rights issues. Individual-level changes enabled field researchers to become aware of and understand stigma and discrimination. In retrospect, they faced stigma while they also did the same to others, whether intentional or not. This was a reflection on this project that **"it's not just a job or a research paper, it's about human value"**.

"This research combined 3 expectations including 1) information indicating level of stigma and discrimination against HIV-positive people and those around them, 2) capacity development for TNP+ staff working on rights issues, and 3) ways to advocate for rights issues in Thailand. It was clear that there were positive changes and increased capacity for expansion of rights work in the future particularly the <u>researchers' better perception on rights and human rights</u>. The examples above exemplify that they could understand human rights, stigma and discrimination through 3 channels which are workshops by the project, self reading and group dialog both formal and informal, and repeated encounter with these phenomena through their friends' experiences and crises."

"Had we not been part of this project, we would have not understood the diverse challenges and complications faced by others. Previously, we could not recognize stigma from looking at or talking with our friends. After hands-on experience implementing the project, we realized it was there and it was rampant. This made us rethink the way we worked and our role in the past."

"During the group work, we didn't really understand our friends. After the research and talking to them, we learned a lot of information."

Some researchers could reflect on the work of the group and the network. *"We only perceived violations within the realm of 'treatment rights' but failed to recognize different aspects of their lives. We only saw pictures of the early days of HIV/AIDS in 1995 when our positive fellows were violated their rights, and only focused on rights of access to treatment and healthcare. The field experience enabled us to see that we had overlooked the everyday stigma but only focused on the bigger issues (which needed to be dealt with, yet among other things) and smaller issues had gone*

unnoticed. In fact, the magnitude of the problem depends on how we see it. Seeing the issue from different angles resulted in different reactions. Some people got used to it (did not see it as a problem, put up with it and chose to deal with themselves instead, i.e. letting it resolve by itself). This later became a complex rooted in their hearts." Nonetheless, this enabled the researchers to understand man's high potential in tolerating pressure or chronic suffering. *"We understood and recognized our friends' ability to bear with tension, loneliness and continued victimization."* This potential, if thoroughly studied, may lead to factors and conditions specific to the Thai society and the understanding of how encounter and coexistence with everyday suffering could persist for years. Though this could be one solution to the problem, it is not an approach to recover humanity through human rights.

Still, acknowledging friends' sufferings through field experience of the researchers was part of the recovery of humanity for our friends. Here are some reflections of the researchers on such acknowledgment. *"The occasion enabled them to realize and recover their own humanity." "If they were stigmatized by people in the society, they were brave to face with them. However, they would deny the encounter in the case of stigma from authorities for fear of repercussions./ Fear of our friends' being disclosed of their HIV status or refusal of treatment by the hospital./ He was the last one seen by the doctor, got upset but did not know what to do. He wrote a complaint, left it in the box but did not know what else to do. If there were someone else or an alliance, he would join."*

Finally, this research added value to stigma work in such ways that the effort to advocate from now on will be concrete and "evidence-based".

"We're not just talking about stigma or only verbally claiming it exists. We have the evidence to support and the analysis to substantiate our claim."

This pilot research serves as a transition for the positive networks. *"The value of a piece of work cannot be easily assessed verbally but this index can determine the value of the lives of our positive fellows including their negative counterparts. This historic value is a transition for the movement by the positive networks in Thailand. We might not be able to solve the problem today, but this will contribute tremendously in the future, providing the networks do not forget this before solution is realized."*

Chapter 3

"Index" of Stigma and Discrimination against HIV-positive People

It's because you're promiscuous….

It's already bad enough to be a transvestite but now you have AIDS…

You're crippled and you also have AIDS…

How did you get this hellish disease?

Your parents have AIDS. You AIDS. AIDS…

These statements above reflect enmity, loathing and disparagement against HIV-positive people that do not happen occasionally but regularly and everywhere. In fact, repetition of these definitions has persisted for over two decades.

"The word promiscuity connotes HIV/AIDS and all sexuality transmitted infections (STI's), and can be interpreted in different ways. Generally, it means to have overly lascivious sexual desire and activities with many people. It refers to people with such obvious behavior especially sex workers who have to have sex with many strangers many times a day almost everyday. Therefore, these people are more prone to STI's and HIV infection than general people.

Presently (1989), it is found HIV infection among sex workers is about 10%. That is, almost 1 out of 10 sex workers is HIV-positive. Infection rates are higher in some other places (i.e. Chiangmai has an infection rate of 48%). Consequently, their clients are regarded as highly promiscuous and at a high risk of infection as only 10 commercial sex visits could bring them HIV (risk ratio is higher in some places at 2-3 visits). Male clients alone who have visited VD clinics and undergone blood tests were found to be infected between 1-10%.

*Therefore, promiscuity is as significant a contributor to HIV transmission as injecting drug use. Hence, discontinuation of such behavior will help prevent transmission of HIV and other STI's. If discontinuation is not possible, condoms should be used to reduce the risk (yet protection is not 100% for condoms can break or tear). While some people say they are not afraid of HIV/AIDS because they do not have such behavior with sex workers but they sometimes sleep with other women besides their wives. Though they do not regard such occasional irregularity as **"promiscuous"**, it is medically still so but only at a different degree for the risk of infection is still there."*

"**Not promiscuous**" in the doctor's definition means to have sex with one's own partner only (monogamous). Thus, adhering to the 3rd Buddhist precept (to abstain from sexual misconduct) is a good HIV prevention method for the general people (who are not injecting drug users).[1]

"One good thing about HIV/AIDS is that it promotes people's observation to such precept more. As some have jokingly put it, "God created HIV/AIDS as a punishment for man's imprudence (i.e. addition to drug and promiscuity), didn't he?"[2]

Some people may disagree and think that was the understanding of the generation 21 years ago when this article was written. Over such period of time, Thailand has changed tremendously. On the surface, the Thai society seems to be sensitive enough to the problem to bring an end to violations from cultural labeling through language and symbol. Many campaign billboards were changed from "AIDS equal

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[1] "Talking the doctor's language" by Pasit Prachavej, Morchaobaan, Vol. 128, 12/1989

[2] New reference

deaths & no cure" or "promiscuity brings AIDS to all" to "AIDS can be prevented with condom" or "early diagnosis of AIDS means treatment". Nonetheless, this pattern of change was only secondary.

The early days perceptions and connotations of AIDS transformed into the dominant discourse today by people and institutions who perceived AIDS as a communicable disease resulting from misconduct or as a disease of the sinful/immoral.

"Affluent Chinese are the new ground zero of HIV transmission because of unprotected promiscuity."[3]

"AIDS transmission still prevails. Stop promiscuity."[4]

This discursive practice that fosters the interrelation between the conception of AIDS and sin has an impact on the perception that "only bad people are infected" that has rooted in the society till today.

The writer did not reject the typical characteristics of HIV that it is a virus spread from human to human and is capable of becoming an epidemic like the cold virus. The issue this research aimed to discuss and interpret, however, was the encodement of HIV and positive people with the devaluation of their humanity on the basis of morality or social misconduct.

Information and figures shown in this chapter confirm the concrete existence of stigma and discrimination against HIV-positive people in relation to sexual norms, religion and Thai tradition in the last 12 months (May 2008 – August 2009). Though these figures may not constitute a complete index for the Thai society, the level and the number of stigma and discrimination incidence against HIV-positive people may lead to the deeper pictorial understanding or develop into better index in the future.

This chapter consists of 3 parts. The first part is about general information about the respondent. The second part is experiential indicators of social stigma, self/internal stigma and discrimination, in addition to protection of rights of positive people through the law, policy and/or enforcement, and consequent changes in the last 12 months. The third part focuses on case studies of HIV-related stigma and discrimination in the last 12 months especially in the cases of blood testing, disclosure and treatment preparation upon signs of symptoms. However, only significant aspects of this information gathered from the questionnaire is presented so as to emphasize the reality of stigma and discrimination.

1) **Respondent's Information**

Table 1: Sex

Sex	No.	%
Male	57	24.46
Female	148	63.52
Others including transvestite, gay, MSM female transgender person	28	12.02
Total	233	100.00

Out of a total of 233 respondents, there were 57 males, 148 females and 28 others (table 1). 57.51% were between 30-39 years old, while the second group of 26.18% was between 40-49 years old. 53.19% of them have been

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[3] Manager Online, 2 August 2005

[4] Kaosod, 11 July 2008

infected between 10-14 years, 29.18% between 5-9 years and only 6.18% have been infected for less than 1 year (table 2).

Table 2: Age

Age	No.	%
Youths of 15-19 years	2	0.86
Adults of 20-24 years	4	1.72
Adults of 25-29 years	24	10.30
Adults of 30-39 years	134	57.51
Adults of 40-49 years	61	26.18
Adults of over 50 years	8	3.43
Total	233	100.00

Table 3 shows that 43.28% of the respondents had prior experience being and used to be part of sex workers, MSM, gays/lesbians, injecting drug users ethnic minorities, transgender persons, migrant workers and inmates. 11.59% had physical disabilities (laving lost a finger or leg, cleft palate or dislocated spine).

Table 3: Orientation or common experience of HIV-positive people

Orientation or common experience	No.	%
MSM	16	6.87
Gay or lesbian	15	6.44
Transgender	9	3.86
Sex worker	30	12.88
Injecting drug user	14	6.01
Refugee	0	-
Vagrant	0	-
Ethnic or hill tribe	12	5.15
Migrant worker	5	2.15
Inmate	1	0.43
Non of the above	131	56.22
Total	233	100.00

Per tables 4 and 5, 52.36% of the respondents had primary education, followed by secondary level at 30.47%. Most did not have stable jobs. They worked part-time, on temporary contracts or full-time but did not have full-time job status. Only 16.31% had real full-time jobs while 20.60 were unemployed. In terms of domicile, most lived in the country or small towns. Only 14.16% lived in the city.

Table 4: Education level

Level	No.	%
Did not receive formal education	13	5.58
Primary	122	52.36
Secondary	71	30.47
University or vocational	27	11.59
Total	233	100.00

Table 5: Employment

Employment status	No.	%
Full-time employment	38	16.31
Part-time employment	52	22.75

Full-time but not employed	20	8.58
Part-time job	74	31.76
Unemployed	48	20.60
Total	233	100.00

57.51% had a family income lower than 5,000 baht per month, followed by 25.32% between 5,000 – 10,000 baht per month. Only 11 households or 4.72% had a monthly family income more than 50,000 baht (table 6). This information corresponds to most respondents' employment on a part-time or occasional basis.

Table 6: Family income

Monthly family income in the last 12 months (baht)	No.	%
< 5,000	134	57.51
5,001 – 10,000	59	25.32
10,001 – 15,000	11	4.72
15,001 – 20,000	9	3.86
20,001 – 30,000	8	3.43
30,001 – 40,000	1	0.43
40,001 – 50,000	-	-
> 50,000	11	4.72
Total	233	100.00

Another important part of personal information that helps us to understand fundamental rights to have a spouse or children includes marital status, sexuality and sexual desire. It provides explanation of the context and needs of HIV-positive people as "humans" who also have these needs. Most respondents, 114 out of 233 or 48.93%, were married or lived with a partner whereas only 24 of the total or 10.30% were single and did not have sexual activity/relationship (table 7).

Table 7: Marital status

Marital status	No.	%
Married or live with a partner	114	48.93
Married but not living together	25	10.73
Have a relationship but not living together	40	17.17
Single (no sex)	24	10.30
Divorced or separated	13	5.58
Widowed	17	7.30
Total	233	100.00

86.29% or 201 of the total responded they had sexual desire. This reflects that sexual desire is a basic human need regardless of sex, age health (table 8).

Table 8: Sexual desire

Sexual desire at present	No.	%
Yes	201	86.27
No	32	13.73
Total	233	100.00

2) Experiential indicators of social stigma and discrimination

This section of the questionnaire seeks to understand the experiences and the level of stigma, both against others and internal. Gathered information revealed that external stigma was not obvious when compared by frequency of occurrence as only 65.67 said they had never been stigmatized against or refused to join social activities (table 9).

Table 9: Refusal or prevention from joining social or community activities

Frequency of refusal or prevention from joining social or community activities in the past 12 months	No.	%
Never	153	65.67
Once	11	4.72
A few times	26	11.16
Often	43	18.45
Total	233	100.00

However, a combination of percentage of all of those refused or prevented from joining social or community activities represents 34.33% of the total. Positive people with this refusal experience think that a significant cause of this was their HIV status (57.84%). Other causes in combination of HIV status represent 17.65% of the total (table 10).

Table 10: Causes of refusal or prevention from joining social or community activities

What do you think are the causes of stigma and discrimination?	No.	%
HIV status	59	57.84
Other reasons	8	7.84
Both	18	17.65
Not sure	17	16.67
Total	102	100.00

In the context of family, the question seeks to identify the frequency of refusal or prevention from joining family activities i.e. cooking or having a meal together. Findings revealed that 87.98% of the respondents had never been refused or prevented as such, signifying acceptance within the family. Nonetheless, 12.02% or 28 of them reported such refusal from family. Among these, 22 reported a high incidence (table 11).

Table 11: Refusal or prevention from joining family activities

Frequency of refusal or prevention from joining family activities in the past 12 months	No.	%
Never	205	87.98
Once	3	1.29
A few times	3	1.29
Often	22	9.44
Total	233	100.00

Rates of stigma became evident in the case of positive people's feeling that they were the gossip subject (table 12).

Table 12: Feeling of being a gossip subject

How often do you feel you have been the gossip subject in the past 12 months?	No.	%
Never	54	23.18
Once	11	4.72
A few times	47	20.17
Often	121	51.93
Total	233	100.00

Table 12 shows that 121 or 51.93% of the respondents had "felt" they were a gossip subject and 51.93% thought they had "often" been such gossip target. 145 or 81.81% of the respondents thought the main reason was because of their HIV status.

55 of those who did believe there were other reasons in addition to HIV status, and that these "other reasons" (table 13) may be associated with their "identity" formed by their experience in life, social status, political status and sexuality (table 14). Some of the respondents interpreted that the causes may also relate to their "behaviors" or lifestyle (table 15).

Table 13: Feelings of having been a gossip subject

If you feel you have been the gossip subject, what do you think could be the reasons?	No.	%
HIV status	90	50.28
Other reasons	15	8.38
Both	55	30.73
Not sure	19	10.16
Total	179	100.00

Table 14: Stigma and discrimination experiences from other causes besides HIV status

Based on your experience, what were the causes of stigma and discrimination besides HIV status	No.	%
Sexual orientation (being MSM, gay)	32	13.73
Being a sex worker	13	5.58
Being an injecting drug user	13	5.58
Being a refugee	0	-
Being a vagrant	0	-
Ethnicity	11	4.72
Being a migrant worker	4	1.72
Being an inmate, detainee or minor in a correction center	2	0.86
None of the above	158	67.81
Total	233	100.00

Table 15: Other factors contributing to stigma and discrimination

Other factors contributing to stigma and discrimination	No.	%
Frequent sickness	9	6.57
Poverty	6	4.38
Never been violated	6	4.38

Habitual night outs, doing sex work at night	5	3.65
Community opposition against second marriage	5	3.65
High turnover of partners, frequently having new or more than one husband	4	2.92
HIV status and poverty	4	2.92
Argument or dispute with neighbor	5	3.65
Not sure	3	2.19
Disability	2	1.46
Others, including perceptions that <u>HIV positive people are bad or not suited to serve as community volunteers, being gay, or having a younger partner</u>	18	13.14

In an attempt to understand the link between discrimination, prejudice and gossip to verbal assault, the researchers found that 52.79% of the respondents never had such experience whereas 47.21% did. Among those who did, 47% were violated a few times and 40% were violated frequently. More than 50% thought HIV status was the main cause of violations (table 16). In case of physical violence, only a limited number of respondents reported such incidence. 87.17% answered No to the question. Of the 30 respondents whose answer was Yes,15 thought physical assault was not based on HIV status as the occurrences involved 6 heterosexual couples, 4 family members and 10 acquaintances (table 18). These people had close relationships that could allow for physical violence.

Table 16: Violence, harm or verbal assault

Have you experienced any violence, harm or verbal assault in the past 12 months?	No.	%
Never	123	52.79
Once	23	9.87
A few times	47	20.17
Often	40	17.17
Total	233	100.00

Table 17: incidence of physical violence

Have you experienced any physical violence in the past 12 months?	No.	%
Never	203	87.12
Once	18	7.73
A few times	10	4.29
Often	2	0.86
Total	233	100.00

Table 18: Actor of violence

Who performed this violence to you?	No.	%
Spouse or partner	12	40.00
Other family members	4	13.33
Acquaintances other than family members	10	33.33
Strangers	4	13.33
Total	30	100.00

In the context of family relationship in connection with stigma, little segregation was found among the members. When asked if they have ever

been psychologically pressured or harassed by their spouse or partner because of their HIV status, 87.12% answered No while the rest of 12.88% answered Yes. Among the latter, 20 or 8.85% "often" experienced such pressure or harassment (table 19).

Table 19: Pressure or psychological harassment from spouse or partner

Have you experienced any pressure or psychological harassment from your spouse or partner because of your HIV status in the past 12 months?	No.	%
Never	203	87.12
Once	6	2.58
A few times	4	1.72
Often	20	8.58
Total	233	100.00

The researchers crossed into personal territory that was significant in the understanding of family relationship dynamic. This was the question of the willingness or refusal to have sex from their spouse or partner. 92.27% had never been refused to have sex with because of HIV status while only 3.43% were so often refused (table 20).

Table 20: Refusal of sexual intercourse

Have you been refused sexual intercourse because of your HIV status in the past 12 months?	No.	%
Never	215	92.27
Once	2	0.86
A few times	8	3.43
Often	8	3.43
Total	233	100.00

Not only did HIV-positive people experience opposition or discrimination based on their HIV status, those around them were also affected. When asked how often their spouse or family members were discriminated because of their HIV status, this is what we found (table 21).

Table 21: Frequency of discrimination against your spouse or family member based on your HIV status

How often have your spouse or family members been experienced discrimination because of your HIV status in the past 12 months?	No.	%
Never	183	78.54
Once	8	3.43
A few times	22	9.44
Often	20	8.58
Total	233	100.00

In synthesizing the questions of stigma and discrimination, the respondents deduced that the possible causes of opposition, prejudice or discrimination against them and their family members were as follows.

Table 22: Causes of stigma and discrimination

What do you think were the possible causes of stigma and discrimination you experienced?	No.	%
Paranoia of infection from me by others	143	22.10
Lack of understanding about transmission modes and the consequence fear of infection from contact or meeting	141	21.80
Perception that HIV infection is shameful and hesitance of association	131	20.20
Religious belief or cultural judgment	32	4.90
Disagreement by others with my lifestyle or behavior	70	10.80
Seemingly HIV-related physical appearance	78	12.00
Not sure or not know why	53	8.20
Total	648	100.00

3) **Access to employment, health services and education**

Access to health services and education is a common issue shared by the general public especially the poor in the city and the country. In this context, poverty means "economic poverty" and "deprived opportunities" resulting from education level, social class and occupation.

As citizens or employees with HIV, not only were they caught in the poverty, they even became poorer. Findings from positive people forced to leave their residence, employment and source of income revealed the following (table 23).

Table 23: Pressure to relocate or move out of their rented living quarters

How often were you forced to relocate or move out of your rented place in the past 12 months?	No.	%
Never	199	85.40
Once	14	6.00
A few times	12	5.20
Often	8	3.40
Total	233	100.00

When asked about loss of jobs (while being employed), other sources of income in the case of own business or being part-time employees, all the 233 respondents reported as follows.

Table 24: Loss of jobs or other sources of income

How often did you lose your jobs (while being employed), other sources of income (in case of your own business) or being treated as part-time employees in the past 12 months?	No.	%
Never	158	67.84
Once	24	10.30
A few times	29	12.45
Often	22	9.44
Total	233	100.00

When investigated further the reasons for such losses, 60.56% of the 109 respondents said it was because of their HIV status and possibly also other factors (table 25).

Table 25: Causes of loss of employment and other sources of income

What were the causes of losing your jobs (while being employed), other sources of income (in case of your own business) or being treated as part-time employees?	No.	%
HIV status	33	30.28
Other reasons	23	21.10
HIV status and other reasons	33	30.28
Not sure	20	18.34
Total	109	100.00

In relation to table 25, when asked about the reasons for loss of employment or sources of income, some respondents indicated their colleagues in addition to HIV status. Out of the 133 respondents who mentioned their employers, 45.13% reported discrimination from their employers based on their HIV status (table 26).

Table 26: Loss of employment or sources of income based on HIV status

If because of your HIV status wholly or partly), what do you think were the reasons you lost your job or source of income?	No.	%
Discrimination by colleagues and employers	35	30.97
Frequent sick leave	14	12.39
Both discrimination and worsening health	16	14.16
Other reasons	48	42.48
Total	113	100.00

In the context of interoffice relation or hiring organization, 61 out of the 233 respondents reported refusal or denial of opportunity to work because of HIV status (table 27).

Table 27: Refusal or denial of opportunity to work because of HIV status

Have you been refused or denied work opportunity because of your HIV status in the past 12 months?	No.	%
Yes	61	26.18
No	172	73.82
Total	233	100.00

Interoffice relationship also links to promotion or awards and is a sensitive issue because such promotion or awards mean improved changes for those bestowed. When asked the question "how often your job or responsibility changed, or you were refused promotion or an award based on your HIV status in the past 12 months?", 27 out of the 233 respondents reported such phenomenon. 5 of them faced it frequently (table 28).

Table 28: HIV status and changes to job responsibility, refusal of promotion or awards.

How often were your job or responsibility	No.	%

changed, refused promotion or awards because of your HIV status in the past 12 months?		
Never	206	88.64
Once	13	5.58
A few times	9	3.86
Often	6	2.15
Total	233	100.00

When asked a relevant question of "termination, suspension from, refusal of admission into school because of HIV status", only 2 respondents reported such experience (table 29).

Table 29: HIV status and impact on education

Were you terminated, suspended or refused admission into school because of HIV status in the past 12 months?	No.	%
Never	231	99.14
Once	1	0.43
A few times	1	0.43
Often	-	-
Total	233	100.00

Access to healthcare services

This is an issue continuously mentioned by the respondents. The research team therefore constructed specific questions including refusal of services and dental care because of HIV status. Table 30 shows that 46 or 19.74% of the respondents had such experience.

Table 30: Refusal of healthcare services and dental care due to HIV status

How often were you refused healthcare services and dental care because of your HIV status in the last 12 months?	No.	%
Never	187	80.26
Once	28	12.02
A few times	13	5.58
Often	5	2.15
Total	233	100.00

There were two other issues regarding healthcare services; namely, family planning and reproductive health. Figures showing refusal to access to these services were interestingly significant as follows (tables 31 & 32).

Table 31: Refusal of family planning services because of HIV status

Were you refused family planning services because of your HIV status in the last 12 months?	No.	%
Yes	32	13.73
No	178	76.39

Not identified	23	9.87
Total	233	100.00

Table 32: Refusal of reproductive health and sexual health services because of HIV status

Were you refused reproductive health and sexual health services because of your HIV status in the last 12 months?	No.	%
Yes	16	6.87
No	217	93.13
Total	233	100.00

The reason for the question regarding reproductive health was because its relevancy to the analysis in the next chapter on reproductive health rights of HIV-positive people.

4) Self/internal stigma[6] and fear of positive people

Though it is rather complex, the research team emphasized the importance of the issue of self stigma. The interview revealed a high level of self stigma of positive people. The questions asked were linked with their daily life, perception of self and others in the contexts of society, morality and norms. The questions mainly asked if the respondents had any of these feelings in the last 12 months because of their own HIV status (tables 33-39).

Table 33: Shame

I feel ashamed.	No.	%
*Yes	149	63.95
*No	84	36.05
Total	233	100.00

Table 34: Guilt

I feel guilty.	No.	%
*Yes	111	47.64
*No	122	52.36
Total	233	100.00

Table 35: Self-blaming

I blame myself.	No.	%
*Yes	100	42.92
*No	133	57.08
Total	233	100.00

Table 36: Blaming others

I blame others.	No.	%
*Yes	71	30.47
*No	162	69.53
Total	233	100.00

Table 37: Low self-esteem

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[6] Means feeling ashamed for being HIV positive, resulting from the way the society judges one's value based on accepted norms and leading to low self-esteem, worthlessness, depression and isolation.

I feel guilty.	No.	%
*Yes	102	43.78
*No	131	56.22
Total	233	100.00

Table 38: Deserve punishment

I feel guilty.	No.	%
*Yes	51	21.89
*No	182	78.11
Total	233	100.00

Table 39: Intention to commit suicide

I feel guilty.	No.	%
*Yes	39	16.74
*No	194	83.26
Total	233	100.00

These attitudes and perceptions of shame, guilt, self-blaming, low self-esteem, deserving of punishment and intention to commit suicide clearly reflect self stigma for being HIV positive and result from the adoption of cultural values accepted by the society. Consequently, these feelings lead to low self-esteem, worthlessness, depression and isolation. This will be further elaborated in this chapter.

Direct impact from self stigma includes the self-degrading feelings, beliefs or thoughts, and self isolation from the society. The question used to gather these responses was "whether the respondents had the feelings of or decided to do any of the following" (table 40-49).

Table 40: Avoidance to join social events

I choose not to join social activities.	No.	%
*Yes	88	37.77
*No	145	62.23
Total	233	100.00

Table 41: Isolation from family and friends

I isolate myself from family and friends.	No.	%
*Yes	52	22.32
*No	181	77.68
Total	233	100.00

Table 42: Decision to quit job

I decide to quit my job.	No.	%
*Yes	45	19.31
*No	188	80.69
Total	233	100.00

Table 43: Decision not to apply for a better job or accept promotion

I decide not to apply for a better job or accept promotion.	No.	%
*Yes	72	30.90
*No	161	69.10
Total	233	100.00

Table 44: Withdrawal from school/training or giving up such opportunities

I withdraw from education or training opportunities.	No.	%
*Yes	51	21.89
*No	182	78.11
Total	233	100.00

Table 45: Decision not to get married

I decide not to get married.	No.	%
*Yes	76	32.62
*No	157	67.38
Total	233	100.00

Table 46: Decision not to have sex

I decide not to have sex.	No.	%
*Yes	40	17.17
*No	193	82.83
Total	233	100.00

Table 47: Decision not to have children or more children

I decide not to have children or to have more children.	No.	%
*Yes	168	72.10
*No	65	27.90
Total	233	100.00

Table 48: Avoidance to go to local healthcare center even when needed

I avoid going to a local healthcare center even when needed.	No.	%
*Yes	63	27.04
*No	170	72.96
Total	233	100.00

Table 49: Avoidance to go to the hospital even when needed

I avoid going to the hospital even when needed.	No.	%
*Yes	34	14.59
*No	199	85.41
Total	233	100.00

Not only did self stigma and negative attitudes affect behaviors, they also impacted on attitudes toward society and social interactions. When asked if they were "afraid these circumstances would occur to them whether they did or not in the last 12 months", the respondents' answers were as follows (table 50).

Table 50: Gossip

Afraid of being gossiped.	No.	%
*Yes	150	64.38
*No	83	35.62
Total	233	100.00

Table 51: Verbal abuse or harassment

Afraid of being verbally abused or harassed.	No.	%
*Yes	134	57.51
*No	99	42.49
Total	233	100.00

Table 52: Physical abuse or harassment

Afraid of being physically abused or harassed.	No.	%
*Yes	62	26.61
*No	171	73.39
Total	233	100.00

Table 53: Physical assault

Afraid of being physically assaulted.	No.	%
*Yes	53	22.75
*No	180	77.25
Total	233	100.00

In response to the question of "whether they were afraid others would refuse to have sex with them because of their HIV status in the last 12 months", 127 out of 233 respondents answered Yes while the rest answered No (table 54).

Table 54: Afraid of refusal to have sex

You were afraid others would refuse to have sex with you because of your HIV status in the last 12 months.	No.	%
*Yes	127	54.51
*No	106	45.49
Total	233	100.00

5) Rights, Law and Policy

In addition to stigma and judgment of human value, questions in this section were also related to the acquired understanding of the respondents about the law and rights issues.

Responses revealed that about 50% of all the respondents had heard of the relevant declarations and laws before but did not understand their implications or relevance to them (tables 55-58)[7].

Table 55: Prior awareness of HIV-related declarations protecting the rights of positive people

Have you ever heard of any declarations protecting the rights of HIV-positive people?	No.	%
*Yes	101	43.35
*No	132	56.65
Total	233	100.00

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[7] Figures deriving from questions and answers in this section should correlate. However, variances may prevail in this research possibly due to the limited experience of the field researchers. For example, some respondents who answered *never* to a question also provided an answer for the next question that was supposed to be answered by those whose answer was *yes* only. Nonetheless, the researchers decided to use these figures as a reference for the intended purpose of the section.

Table 56: If yes, have you ever read or discussed about them with others?

If yes, have you ever read or discussed about these declarations with others?	No.	%
*Yes	80	54.42
*No	67	45.58
Total	147	100.00

Table 57: Awareness of law, policy or implementation of "national health security act 2002"

Have you ever heard of the law, policy or implementation of the national health security act 2002?	No.	%
*Yes	168	72.10
*No	165	27.90
Total	233	100.00

Table 58: Reading or discussion about "HIV-related rights under the national health security act 2002"

If aware, have you ever read or discussed about "HIV-related rights under the national health security act 2002"?	No.	%
*Yes	155	79.08
*No	41	20.92
Total	233	100.00

The awareness or unawareness of the substance of the act regarding rights of HIV-positive people presented an interesting question of how they reacted to the violations of their rights, whether cognizant of such violations or not. Or if aware, how they handled social power and structure. This, therefore, directed the questions to the experiences of positive people in connection with "violations" (tables 59-61).

Table 59: Phenomena resulting from HIV status

Has any of these incidents happened to you in the last 12 months because of your HIV status?	No.	%
Undergoing compulsory medical /health services (including HIV test)	33	14.00
Refusal of a health or life insurance application because of HIV status	50	21.20
Being arrested or going to court on HIV-status related charges	2	0.80
Having to disclose my HIV status in order to enter a country	3	1.30
Having to disclose my HIV status in order to apply for citizenship or residency in a country	1	0.40
Being grounded, quarantined, deserted or isolated	18	7.60
None of the above	129	54.70
Total	236	100.00

Table 60: Violations resulting from HIV status

Have your rights been violated because of your HIV status in the last 12 months?	No.	%

Yes	110	47.21
No	73	31.33
Not sure	50	21.46
Total	233	100.00

Table 61: In case of violations, attempts to lodge complaints or for corrections according to the law in order to maintain the entitled rights

If violated, did you try to lodge a complaint or legal corrective measure according to the rights you are entitled to as an HIV-positive person?	No.	%
Yes	21	13.29
No	118	74.68
Not sure	19	12.03
Total	158	100.00

In the last 12 months, 25 respondents lodged complaints (table 62), 17 cases of which were corrected, 4 of which were in process and another 4 cases did not progress (table 63).

Table 62: Lodging legal complaints

Were there any complaints lodged in the last 12 months?	No.	%
Yes	168	72.10
No	65	27.90
Total	233	100.00

Table 63: Results of the complaints

What were the results of the complaints?	No.	%
Resolved	17	68.00
In process	4	16.00
Nothing happened	4	16.00
Total	25	100.00

Because of the following reasons, some respondents never or were not sure if they had tried to lodge complaints or corrective measures (table 64).

Table 64: Reasons for not attempting to lodge complaints or corrective measures

What was your reason for not lodging complaints or trying corrective measures?	No.	%
Not having enough money to pursue such action	11	8.03
Complicated process and amount of time taken	19	13.87
Threat or fear from pursuing such action	5	3.65
Advice from someone to just ignore it	6	4.38
No or little confidence of successful result	64	46.72
None of the above	32	23.36
Total	233	100.00

As shown, the main reasons for abandoning their rights were because of lack of confidence in the anticipated success. This was a structural challenge. Those with no or little confidence accounted for 64 or 46.72% while those

perceiving the process as being too complicated and time-consuming constituted 13.87% or 19 of the total (table 64).

The figures below (table 65) reflect the lack of confidence in the mechanism addressing violations against positive people and their consequent attempted complaints. Responses revealed that 161 out of the 233 respondents never lodged a complaint while only 72 of them had.

Table 65: Complaints to authority about violations against positive people

Have you ever lodged a complaint to the authority about a violation because of your HIV status?	No.	%
Yes	72	30.90
No	161	69.10
Total	233	100.00

55 out of the 72 respondents lodged their complaints in the last 12 months (table 66), of which 35 cases or 48.61% were resolved whereas 20 cases or 27.78% were in process. Nothing happened to the remaining 17 cases or 23.61% after the complaints (table 67).

Table 66: Complaints to authority

Have you lodged a complaint to the authority in the last 12 months?	No.	%
Yes	55	76.39
No	17	23.61
Total	72	100.00

Table 67: Results of the complaints

What were the results of the complaints?	No.	%
Resolved	35	48.61
In process	20	27.78
Nothing happened	17	23.61
Total	72	100.00

Besides the authorities, protection or prevention of positive people from violations may also involve local and national-level politicians. To find out, a question of whether they had ever tried to involve local and national-level politicians in resolving these violation issues was asked. Out of the 159 responses, only 30 of them tried to resort to politicians (table 68). 26 of them happened in the last 12 months (table 69). 15 cases or 50% were resolved, 12 cases or 40% were in process while nothing happened to the other 3 cases or 10% (table 70).

Table 68: Complaints to local or national-level politicians

Have you ever tried to involved local or national-level politicians in resolving violations resulting from your HIV status?	No.	%
Yes	30	18.87
No	129	81.13
Total	159	100.00

Table 69: Such complaints in the last 12 months

These complaints happened in the last 12 months?	No.	%
Yes	26	86.67
No	4	13.33
Total	30	100.00

Table 70: Results of the complaints

What were the results of the complaints?	No.	%
Resolved	15	50.00
In process	12	40.00
Nothing happened	3	10.00
Total	30	100.00

6) Consequences contributing to change

This section summarizes the reactions from the respondents to the stigma, discrimination and violations against them, and explains the linkages of such negative interactions. When asked if they have faced, experienced or educated people who stigmatized and discriminated against them in the last 12 months, 131 or 58.22% of the 225 respondents counteracted those who had negative interactions with them (table 71).

Table 71: Facing, challenging or educating those stigmatizing and discriminating against HIV-positive people

Have you faced, challenged or educated people who stigmatized or discriminated against you in the last 12 months?	No.	%
Yes	131	58.22
No	94	41.78
Total	225	100.00

119 out of the 131 respondents knew groups or organizations providing assistance in cases of violations. These groups and organizations are varied but mostly HIV-positive support groups (table 72).

Table 72: Support groups or organizations known by respondents in case of violations[9]

Known support groups or organizations	No.	%
HIV-positive groups	189	25.00
HIV-positive networks	171	22.60
Local non-governmental organizations	96	12.79
Religious organizations	49	6.50
Legal institutions	64	8.50
Human rights organizations	57	7.50
National non-governmental organizations	49	6.50
National HIV/AIDS Committee	36	4.80
International non-governmental organizations	18	2.40
The United Nations	14	1.90
Others	12	1.60

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[9] Can answer more than one choice.

Total	755	100.00

Other organizations besides HIV-positive groups that the respondents sought help from include Médecins Sans Frontières (MSF), Rainbow Sky Association of Thailand (RSAT), Alden House, Foundation for AIDS Rights (FAR) and healthcare staff assisting support groups. This information shows that organizations supporting and known by HIV-positive people exist. When asked if they sought help from these organizations, 83 respondents answered Yes (table 73).

Table 73: Seeking help from organizations when stigmatized or discriminated

Did you seek help from organizations for the stigma and discrimination against you?	No.	%
Yes	83	37.22
No	140	62.78
Total	223	100.00

In addition to other organizations, support groups and networks also provided help for each other. When asked if *"they had helped other positive people in the last 12 months"*, 187 or 83.86% answered Yes (table 74).

Table 74: Providing support to other positive people

Have you provided support to other positive people in the last 12 months?	No.	%
Yes	187	83.86
No	36	16.14
Total	223	100.00

Support provided between positive friends was mainly moral support, counseling and sharing of experience. Some forms of physical support included money, food or referral assistance or advice on other sources of support. This peer support within groups and networks continuously prevailed for there were only 16 out of the total 223 that were not members of the groups. The other 217 respondents were members of groups and networks at different levels (table 75).

Table 75: Membership of positive groups and networks

Are you a member of a positive group or network?	No.	%
Yes	217	93.13
No	16	6.87
Total	223	100.00

Besides the support among friends within groups and networks, this research study revealed that participation in networks or projects supporting positive people, both governmental and in the private sector, allowed opportunity for positive people to be involved in the effort to improve the law, policy and practice related to HIV/AIDS. 103 or 44.21% of the respondents said that they had the opportunity to be part of such effort in the last 12 months (table 76).

Table 76: Involvement in legal reform

Have you been involved in any effort to improve the law, policy or practice related to HIV/AIDS in the last 12 months?	No.	%

Yes	103	44.21
No	130	55.79
Total	223	100.00

This involvement increased the confidence for the groups and networks to advocate for better policy and structural reform as shown on table 77 below. This was based on the question of the "matters they thought they had power to negotiate"[10].

Table 77: Negotiation power

Matters I think I have power to negotiate.	No.	%
Law or rights impacting positive people	158	22.50
Local authorities' policies impacting positive people	121	17.30
Local projects benefiting positive people	111	15.80
Central government's policy impacting positive people	101	14.40
National projects or plans benefiting positive people	73	10.40
International declarations or agreements	85	12.20
None of the above	52	7.40
Total	701	100.00

When asked what was key to the solution of stigma and discrimination should organizations working on HIV/AIDS and protection of positive people's rights be supported to do their work, the answers were diverse and varied yet emphasized the importance of raising awareness about HIV/AIDS for the general public (table 78).

Table 78: Recommendations for positive networks and organizations in solving stigma and discrimination issues

A number of positive organizations are fighting stigma and discrimination. If they ask you "the most important key to the solution of stigma and discrimination issues," what will be your answer?	No.	%
Commitment to improve positive people's rights	42	18.03
Psychological and physical support to positive people, including advice on services available	29	12.45
Dedication to the improvement of rights of/support to people with risk behaviors (MSM, IDU)	31	13.30
Knowledge sharing with positive people about living a positive life	50	21.46
Raising awareness on HIV/AIDS for the public	81	34.76
Total	233	100.00

This chapter has presented a pictorial phenomenon of stigma and discrimination, and experiences of positive people. Clearly, stigma and discrimination exist on a large and diverse scale. It has continuously intensified the resistance between social relations for over 20 years. The next chapter will discuss the tangible consequences of stigma and attitudes against HIV/AIDS, positive people and those associated with

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[10] Can answer more than one choice.

them. These attitudes and behaviors lead to the "violations" against the rights of positive people who are also humans and citizens of a country.

Chapter 4

"Violation", Violence on the Passage of Culture

In various small areas of Thailand in 2009, the following incidents occurred.

*"They announced through public address system asking me to collect **HIV/AIDS stipend**."*

*"The local health center staff told others we're **infected**."*

*"They **refused our application for community healthcare volunteers** because we're positive."*

*"My office imposed **compulsory HIV testing**."*

*"They verbally harassed me for **having a husband and being infected with HIV**."*

*"My kid was **refused admission to school** because of other parents."*

*"I used my car as a guarantee for a bank loan but someone in my **family told the loan company of my HIV status**."*

This chapter is crucial for the learning process of the researchers as they found "violations" of positive people's rights are prevalent in the Thai society as indicated by the research hypothesis. The knowledge acquired through the experiences of the research team and the respondents reiterate the reality of humanity and the associated dehumanization resulting from HIV status. This has enabled the research team to conclude that "cultural" factors are significant in the determination of the humanity and dignity of positive people.

The word "culture" in this research is different from the conventional definition of values or virtues deserving preservation, or traditions passed on from one generation to another. However, "culture" in this context means a set of shared experiences under a set of cultural values that constitute social norms and relationships. Therefore, to understand "culture", different forms of social interactions or such expressions in a specific contextual relationship must be understood (Apinya Fuengfusakul, 1998).

Based on this context, the course of stigma against positive people may be outlined as follows.

"Culture" → cultural values → judgments → stigma → discrimination → dehumanization (positive people's reaction to such phenomenon) → protection of fundamental rights and freedom → upholding humanity and human rights

The trail of stigma and reaction above shows that to understand the phenomenon it is important to understand the linkages between such phenomenon and the socially accepted shared values. And through this phenomenal trail one will understand that the process of awareness building and shaping that brings the people to the conclusion that "AIDS equals death or sinful people deserve this punishment" has firmly rooted in the society.

This chapter explains the linkage between the factors and cultural conditions that foster violation of rights, whether intentional or not. People's ignorance of their violations against other prevails because of their unawareness that they are trapped by a cultural confinement. Apinya Fuengfusakul (1998) compared that culture is like water and people are the fish. We live in the water all our lives so we don't know the water thoroughly. Once we get to go onto the land, we will see and understand the definition of the water more clearly, in addition to the extent of its importance and implication to our life. Similarly, this chapter aims to provide a different angle to the

understanding of the cultural process of violations through the relationships of all the 233 respondents in different contexts.

1) **Blood testing and diagnosis**
   In the case of HIV, blood testing means more than just diagnosis of an illness because the branded value of positive people creates fear and threat for ensuing and future circumstances. Experiences of others cause us to think about what can happen to us when our status changes from a friend, parent, sibling, cousin, etc., to a HIV-positive person. When asked about the reason for blood testing, the answers varied and were intentional, unintentional and compulsory (table 79).

Table 79: Reasons for blood testing

Reasons to undergo a blood test for HIV?	No.	%
Employment	14	4.60
Pregnancy	54	17.08
Pre-nuptial/sex preparation	3	1.00
Referral by a VD clinic	8	2.60
Referral as a result of HIV-related symptoms	74	24.30
Positive blood test result of a family member	35	11.50
Illness or death of a spouse, partner or family member	54	17.80
Curiosity	43	14.10
Others	19	6.30
Total	233	100.00

From the table, only 43 respondents or 14.10% chose to have a blood test out of their own curiosity. The rest did so because of a requirement or a necessity at various levels all the way up to a decision by a concerned party. Particularly, 74 respondents or 24.30% were referred for a blood test because of HIV-like symptoms.

However, when asked again if they decided to take the test at their own will, 51.93% answered Yes (table 80).

Table 80: Decision to undergo HIV test

Did you make your own decision to undergo a HIV test?	No.	%
Yes, it was my own decision.	121	51.93
I made the decision under someone's pressure.	36	15.45
I was forced to do so.	20	8.58
I had the test unknowingly and learned I did it later.	56	24.03
Total	233	100.00

Pre and post-test counseling was an important step especially if the person was not willing to take the test. Nonetheless, the interviews revealed that 48 respondents or 20.60% did not receive any counseling while 81 or 34.76% received counseling after the test. Less than 50% received counseling both before and after the test (table 81).

Table 81: Counseling and HIV testing

Did you receive any counseling in the HIV blood testing process?	No.	%

I received both pre and post-test counseling	99	42.49
I received only pre-test counseling	5	2.15
I received only post-test counseling	81	34.76
I did not receive counseling at all	48	20.60
Total	233	100.00

Counseling in this very context does not include the quality aspect of it or the contents crucial to the clients. Thus, the comprehensiveness of the counseling may be rather limited (and possibly also quality) in order to accommodate the reality of a positive result.

2) Disclosure and confidentiality
Disclosure and confidentiality are a direct result of violation or respect for positive people's rights. Interviews revealed that disclosure of HIV status without consent or approval occurred. Self-disclosure corresponds to the level of intimacy. In case of spouses, 67.81% of positive people disclosed the status by themselves. This percentage reduces to 62.50% in case of family members and 24.46% in case of neighbors. 29.57% of respondents disclosed their status to their colleagues and only 19.65% of them did so to their employers (tables 82-97).

The information gathered may vary in terms of numbers in relation to percentage as a result of individual contexts. For example, if the case was not between an employer and an employee, they did not answer the question. Therefore, these tables explain both the relationship and the relativity based on different individual connections. The question that resulted in these figures was "how these people knew of their HIV status".

Table 83: Others' awareness of my HIV status

Spouse or partner	No.	%
From me	158	67.81
From others with my consent	11	4.72
From others without my consent	9	3.86
They did not know my HIV status	15	6.44
Did not disclose	40	17.17
Total	233	100.00

Table 84: Awareness of my HIV status (other adults in the family)

Other adults in the family	No.	%
From me	145	62.50
From others with my consent	22	9.48
From others without my consent	24	10.34
They did not know my HIV status	27	11.64
Did not disclose	14	6.03
Total	232	100.00

Table 84: Awareness of my HIV status (children in the family)

Children in the family	No.	%
From me	81	34.91
From others with my consent	15	6.47
From others without my consent	21	9.05
They did not know my HIV status	54	23.28
Did not disclose	61	26.29
Total	232	100.00

Table 85: Awareness of my HIV status (friends/neighbors)

Friends/neighbors	No.	%
From me	57	24.46
From others with my consent	19	8.15
From others without my consent	86	36.91
They did not know my HIV status	41	17.60
Did not disclose	30	12.88
Total	233	100.00

Table 86: Awareness of my HIV status (other positive people)

Other positive people	No.	%
From me	156	66.95
From others with my consent	31	13.30
From others without my consent	20	8.58
They did not know my HIV status	13	5.58
Did not disclose	13	5.58
Total	233	100.00

Table 87: Awareness of my HIV status (colleagues)

Colleagues	No.	%
From me	68	29.57
From others with my consent	14	6.09
From others without my consent	35	15.22
They did not know my HIV status	48	20.87
Did not disclose	65	28.26
Total	230	100.00

Table 88: Awareness of my HIV status (employer/supervisor)

Employer/supervisor	No.	%
From me	45	19.60
From others with my consent	6	2.62
From others without my consent	32	13.97
They did not know my HIV status	52	22.71
Did not disclose	94	41.05
Total	229	100.00

Table 89: Awareness of my HIV status (clients)

Clients	No.	%
From me	19	8.23
From others with my consent	10	4.33
From others without my consent	20	8.66
They did not know my HIV status	50	21.65
Did not disclose	132	57.14
Total	231	100.00

Table 90: Awareness of my HIV status (my IDU friends sharing the needle with me)

My IDU friends sharing the needle with me	No.	%
From me	32	13.79
From others with my consent	7	3.02
From others without my consent	11	4.74
They did not know my HIV status	22	9.48
Did not disclose	160	68.97

	232	100.00
Total	232	100.00

Table 91: Awareness of my HIV status (religious leaders)

Religious leaders	No.	%
From me	44	18.88
From others with my consent	19	8.15
From others without my consent	19	8.15
They did not know my HIV status	54	23.18
Did not disclose	97	41.63
Total	233	100.00

Table 92: Awareness of my HIV status (community leaders)

Community leaders	No.	%
From me	73	31.47
From others with my consent	31	13.36
From others without my consent	42	18.10
They did not know my HIV status	35	15.09
Did not disclose	51	21.98
Total	232	100.00

Table 93: Awareness of my HIV status (public health staff)

Public health staff	No.	%
From me	145	62.50
From others with my consent	28	12.07
From others without my consent	26	11.21
They did not know my HIV status	7	3.02
Did not disclose	26	11.21
Total	232	100.00

Table 94: Awareness of my HIV status (social workers/counselors)

Social workers/counselors	No.	%
From me	131	56.22
From others with my consent	23	9.87
From others without my consent	19	8.15
They did not know my HIV status	20	8.58
Did not disclose	40	17.17
Total	233	100.00

Table 95: Awareness of my HIV status (teachers)

Teachers	No.	%
From me	45	19.31
From others with my consent	13	5.58
From others without my consent	26	11.16
They did not know my HIV status	47	20.17
Did not disclose	102	43.78
Total	233	100.00

Table 96: Awareness of my HIV status (government officials)

Government officials	No.	%
From me	29	12.45
From others with my consent	22	9.44
From others without my consent	13	5.58
They did not know my HIV status	44	18.88

	125	53.65
Did not disclose	125	53.65
Total	233	100.00

Table 97: Awareness of my HIV status (media)

Media	No.	%
From me	23	9.87
From others with my consent	14	6.01
From others without my consent	7	3.00
They did not know my HIV status	46	19.74
Did not disclose	143	61.37
Total	233	100.00

The cases of "disclosure without consent", which are deemed as a violation, represent a large number of the total violations when combined together into a new table. Though these numbers mat not be construable in terms of percentage as there could be redundancy from the same respondents, they exhibit the distribution and phenomena of the linkages at community level where different groups of people became aware of the test result (table 98).

Table 98: Awareness of my HIV status without my consent

Disclosure by others without my consent	No.
Spouse/partner	9
Other adults in the family	24
Children in the family	21
Friends/neighbors	**86**
Other positive people	20
Colleagues	35
Employer/supervisor	32
Clients	20
IDU friends with whom I share the needle	11
Religious leaders	19
Community leaders	**42**
Public health staff	26
Social workers/counselors	19
Teachers	26
Government officials	13
Media	6
Total	**410**

Though this total of 410 respondents is not statistically significant, it reflects the **"size of violation"** against different groups of positive people in relation to the challenges for which they sought help from organizations as mentioned in the last chapter. These challenges captured various violation issues which can be grouped into 5 categories as follows.

1) Basic information
    -   Living together and HIV transmission
    -   Basic healthcare
    -   Anti-retroviral drugs
    -   Side effects of drugs
2) Co-existence in the society
    -   Making known of HIV status to others
    -   Stigma from community or related to drug use

- Refusal to be accepted as community leaders
- Reactions from noodles seller and other customers
- Refusal to joining cooking for a community religious event
- Gossip by others in the same community
- Someone said not to buy things from you
- They said I was promiscuous and bad
- Physical assault
- Food seller afraid of transmission from us
- Children refused to go to school because of other parents

3) Demand for and access to benefits
- Treatment rights
- Access to treatment
- Healthcare staff's refusal to prescribe ARV's if alcohol and cigarette not abstained

4) Acceptance to a group or association
- Membership to community funeral funds
- Membership to agricultural and cooperative bank and funeral bank

5) Discrimination and violation
- Doctor's discrimination against positive patients
- Discrimination from hospital staff
- Disclosure to others without consent
- Disclosure by staff of sub-district administrative office, hospital or health center to the public
- Disclosure of blood test result by healthcare staff
- Being the last on the list for cervical cancer checkup (doctor said cannot allow HIV-positive person first because equipment was expensive)
- Posting list of positive people in public to collect monthly stipend
- Hospital staff told others of our stories
- Refusal to join village healthcare volunteer group
- Refusal to be invited to village/community events
- Compulsory HIV testing for job application
- Blood testing required by company
- Prejudice against HIV-positive Burmese
- Plan to use own car as guarantee for a load refused because of disclosure to company by someone in the village
- Compulsory disclosure to partner
- Disclosed as HIV-positive and accused of being a drug user
- Told to leave vendor space by owner when HIV status known
- Harassment for having a husband and HIV at the same time

Disclosure of status of HIV-positive people is like two sides of a coin as it creates uncertainty if they can actually disclose. Almost 100% of positive people want to disclose their status by themselves when they are ready based on their relationships within their own family, social and economic statuses, etc. However, when asked how often they were "pressured to disclose their status by people around them", the followings were found (tables 99-101).

Table 99: Pressures to disclose HIV status

How often did you feel pressure from other HIV-positive people, groups or networks to disclose your status?	No.	%
Often	17	7.30

A few times	20	8.58
Once	10	4.29
Never	186	79.83
Total	233	100.00

Table 100: Pressure from other HIV-negative people

How often did you feel pressure from other HIV-negative people, family members, social workers, or NGO staff to disclose your status?	No.	%
Often	23	9.87
A few times	29	12.45
Once	22	9.44
Never	159	68.24
Total	233	100.00

Table 101: Disclosure of your status by healthcare staff

Has your status been disclosed by healthcare staff i.e. doctor, nurse, counselor or lab technician, to others?	No.	%
Yes	57	24.46
No	98	42.06
Not sure	78	33.48
Total	233	100.00

The numbers of the answers yes, a few times, once or often represent the size of the pressure on disclosure and the fact that proper disclosure conditions were not in place. Nonetheless, their answers to the question of self-esteem after disclosure were good and positive. 166 or 71.24% of the respondents felt more self-assurance after disclosure of their status to others (table 102).

Table 102: Does disclosure increase self-esteem?

Did you feel the disclosure increased your self-esteem?	No.	%
Yes	166	71.24
No	27	11.59
No information	40	17.17
Total	233	100.00

To find out about reactions of positive people after disclosure of their status, both intentional and unintentional, we asked the question of "reactions of others after knowing your status" and found the following (table 103-118).

Table 103: Reactions of others after learning your HIV status (spouse/partner)

Spouse/partner	No.	%
Strong discrimination	4	1.72
Slight discrimination	12	5.15
Indifferent	49	21.03

Slightly supportive	31	13.30
Very supportive	69	29.61
No good answer	16	6.87
No information	52	22.32
Total	233	100.00

Table 104: Reactions of others after learning your HIV status (other adults in the family)

Other adults in the family	No.	%
Strong discrimination	12	5.17
Slight discrimination	24	10.34
Indifferent	44	18.97
Slightly supportive	61	26.29
Very supportive	56	24.14
No good answer	10	4.31
No information	25	10.78
Total	232	100.00

Table 105: Reactions of others after learning your HIV status (children in family)

Children in family	No.	%
Strong discrimination	3	1.29
Slight discrimination	8	3.43
Indifferent	42	18.03
Slightly supportive	52	22.32
Very supportive	26	11.16
No good answer	21	9.01
No information	81	34.76
Total	233	100.00

Table 106: Reactions of others after learning your HIV status (friends/ neighbors)

Friends/neighbors	No.	%
Strong discrimination	20	8.58
Slight discrimination	44	18.88
Indifferent	44	18.88
Slightly supportive	53	22.75
Very supportive	11	4.72
No good answer	10	4.29
No information	51	21.89
Total	233	100.00

Table 107: Reactions of others after learning your HIV status (other positive people)

Other positive people	No.	%
Strong discrimination	3	1.29
Slight discrimination	6	2.58
Indifferent	62	26.61
Slightly supportive	113	48.50

	28	12.01
Very supportive	28	12.01
No good answer	5	2.15
No information	16	6.86
Total	233	100.00

Table 108: Reactions of others after learning your HIV status (colleagues)

Colleagues	No.	%
Strong discrimination	-	-
Slight discrimination	20	8.58
Indifferent	39	16.74
Slightly supportive	43	18.45
Very supportive	12	5.15
No good answer	15	6.44
No information	104	44.64
Total	233	100.00

Table 109: Reactions of others after learning your HIV status (employer/ supervisor)

Employer/supervisor	No.	%
Strong discrimination	7	3.00
Slight discrimination	16	6.87
Indifferent	21	9.01
Slightly supportive	27	11.59
Very supportive	14	6.01
No good answer	16	6.87
No information	132	56.65
Total	233	100.00

Table 110: Reactions of others after learning your HIV status (clients)

Clients	No.	%
Strong discrimination	5	2.15
Slight discrimination	10	4.29
Indifferent	14	6.01
Slightly supportive	16	6.87
Very supportive	10	4.29
No good answer	18	7.73
No information	160	68.67
Total	233	100.00

Table 111: Reactions of others after learning your HIV status (IDU friends sharing the same needle)

IDU friends sharing the same needle	No.	%
Strong discrimination	3	1.30
Slight discrimination	7	3.04
Indifferent	16	6.96
Slightly supportive	16	6.96

Very supportive	6	2.61
No good answer	20	8.70
No information	162	70.43
Total	233	100.00

Table 112: Reactions of others after learning your HIV status (religious leaders)

Religious leaders	No.	%
Strong discrimination	2	0.86
Slight discrimination	6	2.58
Indifferent	24	10.30
Slightly supportive	33	14.16
Very supportive	8	3.43
No good answer	24	10.30
No information	136	58.37
Total	233	100.00

Table 114: Reactions of others after learning your HIV status (healthcare staff)

Healthcare staff	No.	%
Strong discrimination	13	5.60
Slight discrimination	25	10.78
Indifferent	33	14.22
Slightly supportive	96	41.38
Very supportive	27	11.64
No good answer	3	1.29
No information	35	15.09
Total	232	100.00

Table 115: Reactions of others after learning your HIV status (social workers/ counselors)

Social workers/counselors	No.	%
Strong discrimination	4	1.72
Slight discrimination	6	2.59
Indifferent	34	14.66
Slightly supportive	105	45.26
Very supportive	28	12.07
No good answer	5	2.16
No information	50	21.55
Total	232	100.00

Table 116: Reactions of others after learning your HIV status (teachers)

Teachers	No.	%
Strong discrimination	2	0.88
Slight discrimination	13	5.73
Indifferent	22	9.69
Slightly supportive	27	11.89
Very supportive	4	1.76

No good answer	23	10.13
No information	136	59.91
Total	227	100.00

Table 117: Reactions of others after learning your HIV status (government officials)

Government officials	No.	%
Strong discrimination	7	3.07
Slight discrimination	10	4.39
Indifferent	22	9.65
Slightly supportive	30	13.16
Very supportive	5	2.19
No good answer	11	4.82
No information	143	62.72
Total	228	100.00

Table 118: Reactions of others after learning your HIV status (media)

Media	No.	%
Strong discrimination	11	4.87
Slight discrimination	4	1.77
Indifferent	20	8.85
Slightly supportive	11	4.87
Very supportive	1	0.44
No good answer	25	11.06
No information	154	68.14
Total	226	100.00

Their HIV status should remain a secret as long as they are not sure of the consequences from disclosure. The interview revealed distrust and fear that their status would be disclosed without their consent. Based on the information given above, there were occurrences of disclosure without consent. Though some of the counting was redundant, all of them still represented violations. The total of 410 violation cases can confirm this. This can be further emphasized by the findings from the question of whether they thought "their secret was still a secret" (table 119).

Table 119: Confidentiality of medical records

Your perception toward the confidentiality of medical records of HIV-positive people.	No.	%
I am sure my medical record is well kept confidential.	55	23.61
I don't know if my medical record is kept confidential.	**117**	**50.21**
I know for sure my medical record is not kept confidential.	**61**	**26.18**
Total	**233**	**100.00**

The percentages of those who knew for sure or were not sure their medical records were kept confidential represent the fact that positive people fear interactions with the hospital. In addition, some OPD cards usually indicate HIV status. Some clearly do so while some use signs that are not difficult to

imply. These records are easily accessible and handled openly. Discussion about HIV status during a medical history examination is not discreet enough.

3) Treatment

HIV treatment has been seriously discussed over the last 10 years due to the advent of ARV's in healthcare setting. This is a result of an advocacy by the public which include positive networks, consumer networks, network of patients with kidney malfunctions, network of cancer patients, and AIDS/health NGOs including AIDS Access Foundation, Thai-Belgian MSF, AIDS Rights Protection Center, the Foundation for Consumers and other public coalitions. These alliances together appealed to the government to solve expensive drug issues by issuing compulsory licensing (CL) in 2006 (Foundation for AIDS Rights, 2007:30), enabling positive people especially those network members to access ARV's under government support.

The issues of "health" and "treatment" brought about a significant paradigm shift in HIV/AIDS. While some people may think "people may not be afraid of AIDS because of the availability of drugs and that promiscuity continues", positive people have a different perspective. They think that this can be an opportunity to revive the humanity of positive people, and that HIV/AIDS should no longer be barrier to any fundamental rights.

This research revealed a different perspective of positive people when it comes to their own health and caring for themselves (table 120).

Table 120: Perception of own health by positive people

Generally, how would you describe your current health condition?	No.	%
Excellent	21	9.01
Very good	43	18.45
Good	100	42.92
Fair	62	26.61
Poor	7	3.00
Total	233	100.00

As can be seen from the table, only 7 or 3% of the respondents think their health is bad while 21 or 9.01% think they have excellent health, in addition to 100 who think they have good health. This correlates with the changed perception from "AIDS means death and no cure" to "AIDS, early diagnosis means treatment". Of the total of 233 respondents, 210 or 90.13% are on different regimens of ARV's (table 121).

Table 121: Treatment with ARV's

Are you on ARV's?	No.	%
Yes	210	90.13
No	23	9.87
Total	233	100.00

In addition to ARV's, HIV treatment also involves opportunistic infections (OI's) treatment. Therefore, positive people need to be knowledgeable in both areas in order to ensure good health. The interview revealed the use of OI drugs. This can be implied that the absence of the use of OI drugs was because of a good health condition, or such use of OI drugs together with

ARV's made them healthy so they were no longer in need of OI drugs. Findings in this regard were as follows (table 122).

Table 122: Use of other drugs with ARV's

Are you using any drugs to treat your opportunistic infections?	No.	%
Yes	76	32.62
No	157	67.38
Total	233	100.00

From table 121, it can be implied that the 23 respondents who were not on ARV's were still healthy enough they did not need ARV's, or they might not have access to them. To find out more about this specific access issue, a probing question was asked. The answers vary possibly because of the lack of clear understanding of the question, hence the discrepancies in the number of those who have access to and those who have the ability to access ARV's (table 123).

Table 123: Access to ARV's

Though not currently on ARV's, you have access to ARV treatment.[1]	No.	%
Yes	178	76.39
No	36	15.45
Not known	19	8.15
Total	233	100.00

In a related access issue, positive people have access to OI drugs that are either free or very affordable as a result of the national health security act passed by the government. A high percentage of 88.84% or 207 respondents have access to OI treatment (table 124).

Table 124: Access to OI treatment

Thought not currently on ARV's, you have access to OI treatment.	No.	%
Yes	207	88.84
No	13	5.58
Not known	13	5.58
Total	233	100.00

In addition to access to ARV's, information dissemination system is also important as positive people's health is not about treatment only, hence the question of whether they received counseling on treatment, sexual health and reproductive health. This revealed that 58.80% or 137 respondents received counseling while the rest did not receive counseling possibly due to lack of access or their own will. What was interesting was the disproportionate ratio between access to counseling and the actual number of those receiving such counseling regarding sexual reproductive health. This represents only 48.50% of the total respondents (tables 125-126).

Table 125: Conversation with treatment officer

Have you had a proper conversation with a treatment officer about your HIV treatment	No.	%

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[1] In this context, access means availability of free ARV's or ability to afford them.

options in the last 12 months?		
Yes	137	58.80
No	96	41.20
Total	233	100.00

Table 126: Conversation with sexual health officer

Have you had a proper conversation with a sexual health officer about sexual and reproductive health, your sexual relationship with others, mental fitness, drug use, etc., in the last 12 months?	**No.**	**%**
Yes	113	48.50
No	120	51.50
Total	233	100.00

4) **Having children**
   "Why you have children when you have AIDS" or **"After this one you should undergo sterilization"** are statements reflecting the attitudes against being positive and having children that the two **"should"** or **"must"** be **"incompatible"**. Regardless of the perspectives, the issue of having children is not a problem for many positive people with physical, economic and social readiness. Many want to pursue it because it is another basic human right. To understand this better, a set of questions was asked (table 127-128).

Table 127: Having children

Do you have children?	**No.**	**%**
Yes	144	61.80
No	89	38.20
Total	233	100.00

Table 128: Children with HIV

If yes, is any of your children HIV positive?	**No.**	**%**
Yes	22	15.28
No	122	84.72
Total	144	100.00

Most of the respondents (144 or 61.80%) have children while those who don't account for a considerable number of the total (89 or 38.20%). It was interesting to understand what they think of having children and if they have ever received any related counseling. The end of this chapter will present the challenges in relation to the desire of having children. This section will focus only on counseling in relation to reproductive health to understand the linkages with the government's or relevant authorities' attitude toward such issue (table 129-132).

Table 129: Receipt of counseling on sexual reproductive health options

Since your HIV diagnosis, have you received any counseling on sexual reproductive health options and having children?	**No.**	**%**
Yes	152	65.24
No	69	29.61
Not provided	12	5.15
Total	233	100.00

Table 130: Advice from healthcare staff to not have children

Since your HIV diagnosis, has any healthcare staff advised you not to have children?	No.	%
Yes	**139**	**59.66**
No	83	35.62
Not provided	11	4.72
Total	**233**	**100.00**

Table 131: Forced sterilization by healthcare staff

Since your HIV diagnosis, has any healthcare staff forced you to undergo sterilization?	No.	%
Yes	**67**	**28.76**
No	155	66.52
Not provided	11	4.72
Total	**233**	**100.00**

Table 132: Imposed conditions for ARV treatment

Were you imposed any conditions prior to ARV treatment?	No.	%
Yes	47	20.17
No	163	69.69
Not provided	7	3.00
Not known	16	6.87
Total	233	100.00

We can see from the tables that this "antithetical attitude" of being positive and having children has been reinforced again and again. While 139 or 59.66% of the respondents were advised not to have children, 67 or 28.76% were forced to undergo sterilization after being diagnosed of HIV. The status also led to a condition for ARV treatment that they must be under birth control before they were allowed to start treatment. 47 or 20.17% of the respondents fell under this condition.

To understand more clearly the intrusion on the decision-making regarding fundamental right of reproduction, a question of "whether they were forced by healthcare staff to do any of the following because of their HIV status in the last 12 months" was posted to especially female respondents (tables 133-135).

Table 133: Pressure or coercion from healthcare staff

To undergo abortion	No.	%
Yes	9	6.10
No	81	54.70
Not provided	1	0.70
Not available	57	38.50
Total	148	100.00

Table 134: Pressure or coercion from healthcare staff

Delivery options	No.	%
Yes	4	2.70
No	80	54.10
Not provided	1	0.70

	63	42.50
Not available	63	42.50
Total	148	100.00

Table 135: Pressure or coercion from healthcare staff

Breast-feeding options	No.	%
Yes	15	10.10
No	64	43.20
Not provided	0	-
Not available	69	46.70
Total	148	100.00

Some questions were ask to find out more about their experiences being on ARV's during pregnancy. There were likely two scenarios. Those who answered may have not been pregnant before or were pregnant before starting ARV's, or they were pregnant before HIV infection. The interview deduced the following information (tables 136-137).

Table 136: Pregnancy and ARV treatment

Have you received ARV's to prevent mother-to-child transmission during your pregnancy?	No.	%
Yes – I received ARV's.	68	45.90
No – I didn't know this was an option.	28	18.90
No – I was refused ARV's.	-	-
No – I could not access ARV's.	8	5.50
No – I was not positive during pregnancy.	44	29.70
Total	148	100.00

Table 137: Provision of mother-to-child HIV prevention information

In addition to ARV's, did you receive any information about safe and healthy pregnancy and being part of the prevention of transmission to your child?	No.	%
Yes	87	58.80
No	61	41.20
Total	148	100.00

5) Challenges faced by positive people
This research project decided on issues that were publicly controversial and central to the movement by positive groups and networks to ascertain a better understanding of issues and challenges faced. These issues include 1) blood testing and diagnosis, 2) disclosure and confidentiality, 3) ARV treatment, and 4) having children. The questions were open-ended to allow respondents to freely express their opinions, feelings and thoughts. Each respondent can give answer to more than one issue/question, hence the discrepancies between numbers in the tables.

These answers, however, led to the understanding of positive people's attitudes and the result of cultural value attached to them.

1) Blood testing and diagnosis
A total of 175 out of 233 respondents provided answers (table 183).

Table 138: Blood testing and diagnosis

	Issues	No.
1	Fear to learn of the test result.	7
2	Fear of prejudice from family, community and a tough life.	22
3	Fear of impact on the family.	1
4	Fear of disclosure of result (knowing the result form a different source than the clinic where testing was performed or having to tell the employer the result).	10
5	Having to undergo blood testing for other reasons i.e. illness, accident, pre-natal care, blood donation, death of spouse or partner, etc., all of which require blood testing before treatment can be determined or provided.	21
6	Direct and indirect compulsory blood testing exists. It should be voluntary.	13
7	Blood testing before or during employment should not be required (some companies impose this).	9
8	HIV testing was done without awareness of consent (especially in the case of migrant workers).	15
9	Treatment and pre/post-counseling services system must be effective.	18
10	Those at risk, i.e. sex workers, should undergo regular blood testing and married spouse should disclose status to partner.	8
11	Confident of no infection, hence no testing / trust in the partner.	5
12	Aware of the risks, wants to know result to know how to take care of the health.	7
13	Blood testing process is complicated and problematic. Medical history examination too detailed and done in presence of others. Expressed prejudice and insulting look by staff.	7
14	Others such as blood testing to join group activity should not be pressured or pushed, staff should be open and direct, etc.	16
	Total	175

2) Disclosure and confidentiality
A total of 185 out of 233 respondents provided answers (table 139).

Table 139: Disclosure and confidentiality

	Issues	No.
1	Fear of rejection, gossip or prejudice from family members.	9
2	Fear of prejudice from community.	43
3	Fear of termination from employment, impact on source of income, i.e. cannot sell things, etc.	6
4	Fear of community impact on family.	3
5	Concerned individuals (hospital staff, liaison, peer leader, etc.) should keep the HIV status confidential / the infected person discloses voluntarily / afraid others will know blood result.	94
6	Not ready / do not want to disclose.	14
7	Disclosure can appeal for sympathy, understanding and strength to handle pressure. It also brings services by the	7

	government. So, a positive person should disclose and be prepared for everything.	
8	Own experience, hence confidentiality well maintained.	5
9	No problems.	12
10	Others / choose to disclose to selected most trusted others disclose status to partner.	1
	Total	194

3) ARV treatment

A total of 204 out of 233 respondents answered the questions (table 140).

Table 140: ARV treatment

	Issues	**No.**
1	Better health after treatment, right regimen, self-study to take care of one's health, self-examination, adherence and discipline to treatment.	39
2	Want a cure.	24
3	Want fewer side effects. Do not want body to look different.	72
4	Want smaller dose, either few times or not everyday for fear of discontinuity and resistance.	33
5	Do not want to take ARV's for the rest of the life.	2
6	Fear of interruption of treatment (migrant workers), change in government policy or increased drug prices.	24
7	Fear others will suspect or know of status or be seen joining positive group activity.	9
8	Doctor or staff do not care about changing the regimen, follow progress or lack of more diverse options. Been resistant to many regimens and fear of future availability. Want to have newer drugs or vaccine.	14
9	(In case of changing regimen) was not part of the discussion or decision making.	5
10	Have not received ARV's (mostly migrant workers).	7
11	Others include standard quality drugs, no need to separate HIV clinic from general clinic, expansion of access to cover people not entitled to government benefits, no prejudice or condition that previous drug users should not get ARV's, or availability of ARV's makes people not afraid of infection.	7
	Total	236

4) Having children

A total of 149 out of 233 respondents answered the questions (table 141).

Table 141: Having children

	Issues	**No.**
1	Fear having children and infecting the babies, prejudice from society against children, refusal to go to school, early death and children become orphaned, inability to raise them.	68

2	Do not want to have children.	10
3	Positive people should not have babies or they'll get infected.	13
4	Advice from staff to not have children, fear of verbal abuse or rejection when become sick.	25
5	Absence of proper counseling for positive people about having children. Advice to undergo sterilization or abortion.	6
6	Direct and indirect compulsory blood testing exists. It should be voluntary.	27
7	Blood testing before or during employment should not be required (some companies impose this).	4
8	HIV testing was done without awareness of consent (especially in the case of migrant workers).	14
	Total	167

Chapter 5

Unshackling the Chain of Stigma

Stigma and discrimination have rooted in the social values and relation dynamics called "culture". Changing a culture is difficult for a culture, be it good or bad, transitions from one place to another all the time.

Consequently, it is difficult to eradicate stigma and discrimination from society. Therefore, this research study only attempts to understand the phenomena and problems faced by positive people in the Thai society from their own perspective, an angle of people who share the same faith, in order to analyze the circumstances and conditions fostering such phenomena in daily life and at structural or institutional levels. It is hoped that such understanding will lead to the development of an index that describes the magnitude and trend of the status quo.

"Index" in this context means a systematic collection of information to acquire an understanding and conclusion of relevant issues, acknowledge the differentiation of the events and evaluate and/or anticipate how the trends are changing. Thus, the data collection was focused on stigma and discrimination incidents in the last 12 months while at the same time looked back at the early days of HIV/AIDS so as to comprehend the progressive development of the phenomena.

This research study has led to the understanding that prejudice, objection, disparagement, dehumanization, etc. have persisted. These phenomena have become more complex. In the early days of the epidemic, stigma and discrimination were direct and straightforward. Over the course of 10 years after the first discovery of an HIV case in Thailand in 1984, people in the society at all levels including doctors expressed their stigma and discrimination as a result of "ignorance". However, during 2007-2008 when data collection for this research study took place and when the general public at all levels have understood better about HIV/AIDS, stigma and discrimination still prevailed. The questions of "why" and "what" contribute to such prevalence remain.

1. **Stigma and Discrimination in the Thai society**
   This research study has revealed the following 4 key findings.

   1) **Stigma and discrimination have remained in the Thai society but transformed to become more diverse and complex.** These include blunt prejudice and opposition and subtle behaviors that may seem nondiscriminatory.

      Blunt stigma and discrimination may include slander, eviction, physical assault, refusal to sell things to, and objection to allow HIV-positive children to go to the same school. We found that 14.60% of the respondents were forced to relocate; 32.19% lost their jobs and sources of income; 26.18% were refused employment because of their HIV status; and 19.37% were refused medical services.

      Stigma and discrimination can also be ambiguous or subtle. Provision of medical and healthcare services in both government and private settings is a case in point. Positive people may not be denied the services but have to be the last to be served though they may have come first. This form of stigma and discrimination presents a different magnitude of violation from refusal or objection as it creates pressure and depression for them. Though the degree of this form of violations is more limited, its impact could be more intense internally. Positive people caught in such a situation have to bear this "cultural violence" exhaustively. They may question why they are treated differently from others while the violators may not see the violence they cause at all because it is disguised in the "acceptance" by the positive people themselves. In this regards, various groups working on HIV/AIDS issues suggest that "universal precaution", a principle of service provision where protection from

transmission is ensured, can help reduce discrimination against positive people.

2) Stigma and discrimination in family, community and everyday violations
The researchers view everyday stigma and discrimination as highly violent because of the attached repetitive nature, whether they are aware or unaware of such violence. In the case of obvious awareness, stigma and discrimination may occur through gossip or slander, i.e. "You AIDS", "You AIDS children" or "AIDS car" (owner is positive). When asked about their stigma and discrimination experiences over the last 12 months, it was found that 34.33% of the respondents were refused to join community activities, 57.84% of whom believed it was because of their HIV status.

Though the questionnaires revealed that 94.85% of the respondents were not hindered from joining religious activities, field records exhibited large-scale prevalence of religion-based stigma. Even religious leaders were not allowed to perform religious ceremonies for them. Or if allowed, the procedures must be minimized. This has caused people who believe in life after death to feel that the souls will suffer in another world.

A phenomenon that is parallel to being positive is gossip. We found that only 23.18% of the respondents were not gossip targets in the last 12 months while the rest were, of whom 57.93% were gossiped frequently. In addition, 47.21% of the total experienced verbal abuse and harassment, of whom 50.91% believed it was because of their HIV status.

On the other hand, some people unknowingly cause stigma and discrimination when negative values are integrated with the goodwill and sympathy of family members and cousins. For example, "See, if you had believed me and gone to school you would have not had AIDS" (grandmother talking to grandchild).

Family and community usually link AIDS to pre-existing attitudes toward people with alternate sexualities (in the context of the same culture). These include sex workers, anyone having sex with someone they are not married to, men who have sex with men, etc., or people normally regarded as different such as drug users either currently or previously, inmates, the disabled, the poor, migrant workers, ethnic groups, etc. Almost 30% of the respondents thought their social status together with their HIV status caused them stigma and discrimination. These statuses include sexual orientation (13.37%), sex work (5.58%), drug use (5.58%) and ethnicity (4.72%).

In the context of everyday stigma, circumstances such as the market, temple, community event, family, hospital, or any public events, etc., can be avoided by positive people. They can choose not to go to those places or join such activities. However, two environments; namely, family and hospital, are where positive people feel under intense pressure for they cannot negotiate or refuse, causing them psychological and mental impact which in turn affects their chronic health conditions. Moreover, the increased living constraints or a change in social behavior by isolating themselves are not without violence as they result in lower self-esteem which eventually causes "self stigma".

3) High-level of self stigma among positive people
Stigma and discrimination gradually become psychologically shackled and intensified by positive people. For example, positive people's avoidance to

face challenges that can lead to social stigma and discrimination may on one hand seem like an attempt to reduce and resolve the problems because they will not come up against pressure or depression. On the other hand, however, the violence from the disagreement on human values does not weaken but becomes more intense because of the positive people themselves. More or less 50% of the responses to some questions clearly indicated positive people felt ashamed of themselves, blamed themselves, felt bad, had less self-esteem, worried about being gossip targets, etc. Overall, 63.95% felt ashamed, 47.64% felt bad, 42.92% blamed themselves, 43.78% had lower self-esteem, 16.74% wanted to commit suicide and 21.89% felt they deserved punishment. When asked about fear or anxiety (though not happening to them), 64.38% of the respondents were afraid of being gossiped, 57.51% were afraid of be slandered or of verbal harassment while 54.51% thought other would shun having sex with them for fear of HIV transmission.

Some people view internal stigma as "assumed" stigma. Shame, self-blaming, worthlessness or depression are all taken for granted or caused by positive people themselves. However, when considering the linkages between factors and conditions causing positive people to dehumanize themselves, one can understand that such assumption is a result of a cultural interaction process whether from personal exposure or others' experiences. Therefore, these factors and conditions must also be taken into account in order to understand self stigma.

4) **Protection of fundamental rights is unrealistic and difficult in the eyes of positive people**
Access to entitled services and legal understanding of protection of their rights in case of violations appear to be very low. As earlier mentioned in chapter 4, violations against positive people exist in various forms including announcing a blood test result in public, disclosing blood test result to others without consent, being judgmental (i.e. positive people should not have children, an attitude and discrimination that positive people need not know anything about pregnancy) or having an attitude when it comes to service provision such as the use of contraceptive measures with people on ARV's (almost all the respondents were on ARV's).

A respondent told the interviewer that he did not experience any stigma and discrimination in the last 1 year. However, when delved further into the answer, the reason he did not experience any stigma or discrimination was because he had been doing things by himself. In this case, self stigma has created total control and complete hindrance. For the last 1 year, he isolated himself at home, avoided meeting or interactions with people if not necessary. *"If you know what you have and people disgust it, you don't have to associate with them"*.

Similarly, when violation of any forms happens, many positive people choose to avoid to protect or demand their rights and think that *"more actions only complicate things so just keep quiet and it will be better"*. Based on the data collected, a number of violation incidents occurred. Of all the respondents,

15.22% - "someone disclosed my status to other colleagues without my consent."
13.97% - "someone told my supervisor without my consent."
24.46% - "healthcare staff disclosed our status to others."
50.21% - did not know if their medical records were kept confidential.

26.18% - knew for sure their medical records were not kept confidential.

While violation numbers represent a high percentage, but in terms of law, knowledge of their rights, policy and any attempts to protect their own rights, 56.65% never heard of any such protection in relation to HIV/AIDS. Those who had (45.58%) never read or discussed about such declarations. A high percentage of 72.10% had heard of the national health security act but 20.92% of them never read its contents.

In relation to violations related to HIV status in the last 12 months, the following incidents were reported. 21.20% were refused an insurance policy application. 47.21% were violated their rights because of HIV status. These figures, if combined with the percentage of those who were not sure if they were violated (21.46%), amount to a high percentage of violated cases. Moreover, 74.68% of those violated never tried to demand a solution per the rights they were entitled to. Another 12.03% were not sure if they had attempted to do so. 46.72% of those who were not sure did not have confidence if they would succeed in their attempt while 13.87% of them thought the complaint process was too complicated and time-consuming.

2. Rights and Violation in the Thai society

The conception of "rights" is often regarded as a western thinking and not something original to Asia or the Thai society. However, if we take it from the perspective that rights are about rules and restrictions abided by people in the same society and their existence or insecurity have an impact on social order, welfare and people living in it (Tanate Arpornsuwan, 2006), we will understand that rights are not something that's "imported" but an agreement that sets a framework of relationships for people. Nonetheless, there are different limits and levels of rights, i.e. "human rights" (fundamental rights as a human being), rights as citizens of a state, rights of a community, etc.

Nowadays, issues about rights have expanded and transitioned into new relationship forms. For example, in the context of medical principles and institutions and through interactions between healthcare providers and patients, there have evolved "patients' rights". "Sexual rights" are another social controversy because of their antagonistic nature to cultural and social norms that discriminate people who deviate from them. The repetition and transition of these norms from one generation to another brings about an unquestioned adoption of a myth that men are created for women and that any alternate sexualities are deviant, atypical, abnormal, etc.

Social rules like this exclude certain groups of people and such exclusion does not only separate people by their genders and sexualities but has attached a set of negative values to them without considering their sexual orientation. Such attachment is linked to Thailand's first HIV/AIDS case which was a man who has sex with men. Hitherto the society has presumed that only transvestites, homosexuals, gays and prostitutes can have AIDS.
Anyhow, the thinking that rights are an imported conception from the West deserves further discussion along with the stigma and discrimination phenomena presented in this research. This is because an understanding of the correlation between these phenomena and the research rationale cannot be acquired from an individual perspective but must take into account the "context" and the "rights

cycle"[1]. The cycle enables one to see the linkages of rights conceptualization, learning, learning system, and channels. Albert Einstein once said, "imagination is more important than knowledge". He further explained that, "Senses enable us to see clearly the relationship between methods and the goal while reasoning alone cannot help us perceive the fundamental and the final goals. Therefore, thorough understanding of these goals, either by way of evaluation or immersion, is the ultimate role religions shall play for the benefits of man's social life"[2].

Thus, *"imagination"* in this context is not about fantasy or assumption but man's potential to understand and determine the scope and direction in order to realize a goal. This requires an understanding of humans as beings that have feelings, reasons, exist under an interactive society, etc.

In linking rights perception to stigma and discrimination, we found that many of the respondents did not stand up to the violations against them. Of all the violated cases, 74.86% of them never attempted to demand their rights or resolve the issues. If combined with the percentage of those who were not sure they were violated, the figure amounts to 86.89%. This reflects the reality that most positive people cannot perceive the rights they are entitled to as humans.

Other responses demonstrate that despite perception or adequate understanding of their rights, the channels did not allow the opportunity for positive people to stand up for themselves. Even if they did, there was no guarantee that they would achieve what they demanded. These obstacles hinder fundamental rights of positive people from protection. Out of those who chose not to do anything to protect their own rights, 46.72% did not have or had little confidence in the chances of success. Another 13.87% deemed the process as being too complicated and slow. Obviously, it can be deemed that the Thai society *lacks* perception of rights and this is true for both the violators and the violated.

This lack of perception of rights by both positive people and the Thai society have fostered and resulted in loose acquisition system and prevention mechanism from violations. As a result, violations persist and prevail everywhere. Even government authorities responsible for the protection of people's rights and human rights require a blood test result and reject positive people from employment.

Figures and personal anecdotes of positive people regarding self stigma are another index of the lack of rights perception in the Thai society. The tolerance that slander, gossip, hindrance, violations, etc., are because of the consequences of their own "karmas" is an example of this. While the Buddhist principles encourage people to let go feelings and try to adhere to inner tranquility by contemplating the causes of such phenomena, it brings them to believe that asking from others is not the answer to their own problem. This circumstance begs the question of how the Thai society can create a platform for rights issues if positive people themselves prefer to deal with their own problem at individual level rather than a concerted effort at a larger scale.

3. **Recommendations**
   1) <u>Acquisition and learning system for the Thai Society</u>

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[1] Further reading, Surasom Kritsanajuta etal, "Health Rights, Human Rights", Social Health Research Bureau, Ministry of Public Health, 2008

[2] Albert Einstein, "Science, Philosophy and Religion", Universal Essence Meeting, New York, 1941

All trainings, publications or any implementation related to "rights" must incorporate the understanding of rights and human rights in related social and cultural contexts. Members of positive networks or people working on HIV/AIDS should employ a multi-dimensional process to building the understanding and awareness of "rights". These dimensions may include the law, politics and culture (as a set of prescribed values for humans and behaviors determining humanity, leading to stigma and discrimination).

The course of stigma from "culture" → cultural values → judgments → stigma → discrimination → dehumanization (positive people's reaction to such phenomenon) → protection of fundamental rights and freedom → upholding humanity and human rights, must be looked at under an exhaustive and appropriate conceptual framework. For example, if a stigma incident is a result of cultural myth and bias that lead to judgment of a positive person's humanity, the solution should focus on the adjustment of the social attitude and perception causing it. Then, law can help fortify and endorse the formal recognition of a rights culture.

2) A concerted rights advocacy effort
We found that stigma is diverse, exists in different forms and occurs continuously in our daily life. It can be broadly classified as 1) stigma that is attached to social moral norms, and 2) stigma that separates and labels something as food or bad, leading to the creation of the otherness and branding the others as deviant.

Based on this research study, not only does stigma against positive people occur merely because of stigma against the virus itself, cultural and social violence faced by positive people intensifies the longstanding social bias among people in the same society, i.e. against sex workers, those committing adultery (especially women), widows, transvestites, drug users, poor people, the unschooled (though a large portion of knowledge derives from out of school system), people of different races, etc.

Therefore, the rights advocacy movement in the Thai society should employ a holistic approach and incorporates issues about AIDS rights, sexual rights, civil rights, etc. It should not be segregated but incorporate the issues of access and violation in relation to social and cultural contexts for bias against positive people does not happen solely because of HIV itself. However, it relates to pre-existing biases especially toward gender and socially and culturally "deviant", "abnormal" or "corrupt" behaviors.

This research study was not meant to produce just a published document but also to provide an opportunity for positive people's self-assessment and understanding of the context in which the movement took place. The journey of 20 years of effort by TNP+ and their quadruple allies consisting of the affected general public, the private sector, the government and the academic sector, has seen the expansion and intensity of the issues.

"Bias against positive people is like the taproot of HIV/AIDS problems whereas each positive person is like a rootlet burrowing everywhere, like bias that spreads ubiquitously. Everyday and self stigma resembles the tip of the rootlet burrowed in more than 600,000 positive people in Thailand and other tens of millions sharing the same faith all over the world".

It is hoped that this research study can serve as the torchlight that illuminates the path to the future development of stigma and discrimination index and violations against positive people's rights. In the research team's view, self stigma should be prioritized and all parties concerned should join hands in finding the solution and remedy for positive people, and empower them so that they can stand up for themselves and defend their dignity. There have been examples of such concerted efforts by positive people to advocate with the government on issues impacting public health, i.e. the push for the government to exercise compulsory licensing (CL). This exemplifies an opportunity where a health crisis can bring about a lesson that the society can transform itself into a rights-conscious society that respects and prioritizes public health.

Stigma, discrimination and violation against positive people require the effort by positive people themselves to be overcome for they are biases that have firmly rooted in the society. Not only do stigma, discrimination and violation exist against HIV/AIDS, they prevail in the forms of bigotry against gender, ethnicity, social status, etc. Therefore, the burden of fighting these cultural prejudices should not be shouldered only by those violated. All stakeholders must be open and willing to learn from positive and stigmatized people who try to unshackle these cultural chains that have fettered and put pressure on them.

Appendices

Project Title	Research on Index of Stigma and Discrimination against HIV-positive People for Human Rights Advocacy
Financial Support	The Joint United Nations Programme on HIV/AIDS (UNAIDS)
Implementer	Thai Network of People Living with HIV/AIDS (TNP+)
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1. Director-General, Rights and Liberties Protection Department, Ministry of Justice
2. Director-General, Communicable Disease Control Department, Ministry of Public Health
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14. Representative from the Global Network of People Living with HIV/AIDS (GNP+)
15. Representative from the International Community of Women Living with HIV/AIDS (ICW)
16. Representative from the Joint United Nations Programme on HIV/AIDS (UNAIDS)
17. Representative from the United Nations Population Funds (UNFPA)
18. Representative from the United Nations Education, Scientific and Cultural Organization (UNESCO)
19. Representative from the United Nations Children's Fund (UNICEF)
20. Representative from the World Health Organization (WHO)

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14. Mr. Satian Tanprom, Coordinator, Foundation for AIDS Rights

Rationale

Stigma and discrimination do not happen by themselves but result from negative social perceptions on things or people. These perceptions eventually transform into stigma that in turn leads to discrimination. In the case of HIV-positive peoples and those associated with them, "stigma" is a condemnatory conceptual imprinting on people deemed by the society as deviant, i.e. adultery, being prisoners of war, or having a different lifestyle from the conventional mainstream (the mentally ill, people of alternate sexualities, etc.). They have also become social-cum-cultural "bias" transitioned from one general to another. Stigma may also be influenced by prejudice against ethnicity, racism or homophobia due to behaviors regarded as atypical by the society.

Someone once compared the violence of stigma to "raining stones". In reality, the stones hurt the mind more than the body. The United Nations Secretary General Ban Ki Moon mentioned the impact of stigma against HIV-positive people that it caused fear and anxiety for positive people to come out in public. Many AIDS patients choose not to seek treatment despite the symptoms that are beyond their ability to

cope with. Thus, stigma has made HIV/AIDS the "silent killer". From this perspective, not only can stigma be caused by violations from others, positive people's negative perception toward themselves has embodied in their mindset and thereby begins to aggravate from within. Positive people become introverted, low-spirited and eventually depressed, a stage where opportunistic infections may have their opportunity.

In addition, some consequences of stigma include income insecurity, loss of job, failure of marriage, fear to live with positive people, abortion and isolation from society. These phenomena, in connection with negative values, reflect self stigma or self-value determination by positive people themselves. The question is why positive people are stigmatized against? The possible answer to such stigma now is possibly because those infected in the early days of the epidemic were people already stigmatized by the society. This precondition links HIV/AIDS to longstanding negative values. 1) Perception that HIV infection relates to behaviors of certain groups of people (homosexuals, drug users, sex workers, promiscuous people) who were already stigmatized. Then, this perception was continuously reproduced as exemplified in such campaigns and slogans as "Promiscuity equals AIDS", "Promiscuity means AIDS and death", or "No Promiscuity, No Needles, No AIDS". 2) HIV/AIDS threatens positive people's lives and people around them. 3) Almost all positive people contracted HIV through sexual transmission. While sexual transmitted diseases are stigmatized for sex is regarded as "amoral", people involved in any infidelities are automatically regarded as "unscrupulous". 4) A lot of information disseminated among the society regarding HIV transmission is not clear, inaccurate and sometimes misleading. 5) HIV infection was regarded as someone's irresponsibility. 6) Religions and beliefs led people to the adoption that HIV infection is a punishment immoral people deserve.

In the early days of the epidemic (global epidemic started in 1980 whereas in Thailand it began in 1990), **AIDS was new** to people and the only thing those concerned could do then in order to curb with the spread was to **create fear** without being aware that such devised image would have fostered the expansion of AIDS-phobia to these days. This phobia has been the culprit of refusal and stigma against positive people and AIDS patients. Each devised image was horrifying. Some of them include such statements as "AIDS is a punishment (for the immoral)", "AIDS is criminal (for innocent victims)", "AIDS is a war (for the fight against the virus)", and "AIDS brings the otherness (causing sicknesses and differentiating positive people from others). Though these images may resemble labeling, the degree of violence caused by labeling is different form that caused by stigma. Nonetheless, they both cause social suffering to positive people. Labeling may occur when the word "risk groups" is used to refer to certain people in the context of HIV prevalence. For example, "our organization prioritizes the use of condoms among the risk groups…", or "Thai men like to sleep with transvestites for there's no need to worry about pregnancy and condom use, despite risk infection". This has led to double stigma for positive men who have sex with men (MSM). Stigma exists in diverse forms and at various levels. For instance, **rules and regulations** refuse entrance into a country or impose blood testing; **being treated differently by medical staff** from other patients in general, i.e. wearing an extra pair of gloves over another or wearing gloves every time touching a positive person's body; disassociation by **employers**; gossip or insult within the **community**; or even from **family** members whether intentional or not.

However, different **contexts** and different **groups of people** present and face different problems. Explaining a phenomenon connected with AIDS and stigma cannot be done in a single context and from one perspective for an impact of stigma derives from a different cultural context. For example, it depends on shared

characteristics of people in a culture, an urban or country setting, individuality, religion, gender, sexuality, age, level of personal knowledge, understanding and attitude toward AIDS, etc. Therefore, these stigma correlations fixed or definite but change based on time, context and people. In 2003, the World Health Organization (WHO) clearly indicated that the AIDS prevention must be parallel with care and support, and that stigma and discrimination in all societies must be reduced.

In the research team's view, the social correlations of stigma and discrimination are complex and difficult to evaluate to understand the linkage to the existing AIDS response. They believe that stigma and discrimination are not a natural scientific fact but a cultural truth, a form of established relationship or consequence of a learning acquisition process in the society. Because "stigma" is a springboard for "discrimination", findings form this research will help increase the understanding of the scope and forms of stigma and discrimination phenomena against positive people in Thailand. They can also be used to develop advocacy tools that can bring about changes at a greater level and determine a direction in which all stakeholders should move toward. Particularly, these findings will benefit the capacity building for positive networks to advance their work in human rights advocacy and translating the knowhow into common practice.

Objectives

1. To study the index of stigma and discrimination against people living with HIV/AIDS in Thailand.
2. To improve the understanding of stigma, discrimination and human rights of the research team who is the core driver of positive rights issues for positive networks in Thailand.
3. To apply the findings to positive rights issues in Thailand.

Sampling Populations

This research study has two broad aims; to increase the knowledge for peer leaders of positive networks and to achieve the index of stigma and discrimination against positive people in the Thai society, hence the following sampling populations.

1. Thirteen peer leaders of positive networks representing different regions of Thailand. They played a key role in the research process by serving as research assistants or field researchers in their respective 10 regions including Bangkok, the Central Region, the Upper North, the Lower North, the Upper Northeast, the Central Northeast, the Lower Northeast, the Upper South, the Lower South and the East.

2. A total of 233 positive respondents who answered the questionnaire. They include both network members and the general public selected from all the regions based on sex, age, education, living locale, personal experience (employment, suffering and sexuality). The diversity and equal distribution of the selection were ensured as shown in the table below.

Province	No.	Key samplings reached
Chantaburi	20	Monks, general public
Chiangrai	20	Minorities, migrants, sex workers, drug users, villagers
Prachuabkirikhan	20	Sex workers, gays, general public, villagers
Korat	21	Sex workers, gays, transgender persons,

		villagers
Ubon Ratchatani	20	General public with emphasis on equal distribution of age ranges
Nongbualampoo	24	General public, youths, sex workers
Chumporn	13	General public, drug users, military conscripts
Phuket	12	MSM, migrant workers, ethnic minorities, urban residents
Naratiwas	5	Drug users, general public, youths
Nakornsawan	20	General public, sex workers, urban residents, with an emphasis on different age ranges
Angthong	20	Laborers, sex workers, farmers, general public, MSM, with an emphasis on distribution of age ranges and occupations
Bangkok	17	Drug users, MSM, sex workers, government officials, citizens on social security
Bangkok	18	Urban residents

Research Framework

This research is based on the completed questionnaires to evaluate internationally standard indicators. Therefore, the questionnaire was carefully developed to ensure quality, inclusivity, comprehensiveness by the following organizations.

1. The Global Network of People Living with HIV/AIDS (GNP+)
2. The International Community of Women Living with HIV/AIDS (ICW)
3. The International Planned Parenthood Federation (IPPF)
4. The Joint United Nations Programme on HIV/AIDS)

The questionnaire consists of 3 main parts. The first part asks general information about the respondent (and family). The second part focuses on the experiences of social stigma, self stigma, discrimination, protection of positive rights through law, policies, enforcement or any acquired changed in the last 12 months. The third part presents the case studies of such phenomena in the last 12 months, especially in the cases of blood testing, disclosure and treatment preparation.

In addition, lessons learned by all the 13 research team members were shared in order to better understand the past and everyday challenges, emotions, feelings, expectations, etc., gathered from the interviews between the interviewers and the interviewees.

Study Method

There were 2 phases of the study.

Phase I included the development of questionnaire, training on the questionnaire, production of questionnaire and data collection. The training was conducted by the research team leader and focused on the conceptions of human rights, stigma and discrimination, understanding of questions, group interpretation of questions, rationale for each question, how to begin and how to conclude the interview.

In the development of the questionnaire, the developer emphasized the assurance of non-violation of the respondent's rights and the step-by-step data collection process based on the User Guide. Consent forms were used to protect the rights of the respondents, whether intentional or not, as follows.

1. Project Introduction – for the respondents to read before deciding to join the activity.
2. Interview consent form.
3. Respondent's personal information and questionnaire serial number (two-digit number for the interviewer, two-digit number for the interviewee and initials were used).
4. Confidentiality Agreement by the interviewer.
5. Confidentiality Agreement by the interpreter (in cases needed).
6. Confidentiality Agreement by the research team leader.
7. Confidentiality Agreement by the data officer.
8. Confidentiality Agreement by the data analyst.

Phase II began the data analysis using the SPSS software and employing integrated analysis technique between quantitative analysis and data interpretation through the linkages between social contexts at different levels, overall social awareness and attitude toward HIV/AIDS and stigma and discrimination faced by people judged or regarded by the society as deviant.

Time Frame: 8 months, from February 2009 – January 2010

No.	Activity	Feb.	Mar.	Apr.	May	Jun.	Jul.	Aug.	Sep.	Oct.	Nov.	Dec.	Jan.
1	Translation and understanding of document, selection of field researchers	▓											
2	Submission of project to IRB	▓											
3	Development of training curriculum		▓										
4	Training of research team		▓										
5	Data collection			▓	▓	▓	▓						
6	Analysis and initial synthesis of data				▓								
7	Compilation, comprehensive analysis and synthesis of findings					▓	▓	▓	▓				
8	Findings presentation at regional level						▓	▓	▓				
9	Production of documents and media							▓	▓	▓			
10	Presentation at national level									▓			
11	Submission of final report												▓
12	Presentation at international level	For example, the International Conference on HIV/AIDS in Asia Pacific in Bali, Indonesia or the XVIII International AIDS Conference											

Expected Outcomes

1. Understanding of index and magnitude of stigma and discrimination against people living with HIV/AIDS and their families
2. Interviewers and interviewees exchange experiences and lessons on prevention from falling prey to self stigma, leading to efforts to reduce stigma and discrimination by networks.
3. Field researchers, as positive network peer leaders, develop their skills and increase understanding of the issues in the Thai context, thereby contributing to the strengthening of the network's efforts.

Interview Verbal Consent Form

This form is to be filled by the interviewer and the interviewee.

I _____
<div align="center">(insert interviewer's name)</div>

hereby am conducting a research on stigma and discrimination experiences of HIV-positive people using a questionnaire given.

I have provided _____ with a CD containing information about research objectives and collection method of this research which forms part of the wider research project being conducted in the country that aims to produce a report on positive people's experiences. The CD also includes types of information being sought, confidentiality assurance method and risks associated with participation in this research.

Before beginning with the questionnaire, I would like to ensure your willingness to voluntary participation and you have received all information necessary for your decision to participate.

This form may contain words you do not comprehend. Please let me know when it comes across during the course of interview so that I can provide explanation. You do not need to decide today whether you want to proceed with this questionnaire. You may discuss with anyone you trust regarding this questionnaire or research.

Should you have any questions or concerns regarding this questionnaire or research, please contact the research team leader whose contact information is as follows.

Name _____

Address _____

_____

_____

_____
<div align="center">(insert team leader's name and other contact details)</div>

However, should you decide to participate and answer this questionnaire, I would ask you questions regarding your experiences as a HIV-positive person, particularly about stigma and discrimination occurred to you in the past. The process should take around 2-3 hours.

Before starting to ask you if you are willing to participate, I would like to inform you that;

1. Your participation must be fully voluntary and that you are the one making the decision.
2. You may choose to omit some questions as you see fit.
3. You may choose to stop the interview at any time.

The information gathered from this interview will be kept confidential to ensure strict confidentiality. I will not write your name on the questionnaire or include any information indicative of personal identification.

Should you like to know any further information regarding measures used to protect your information, please do not hesitate to let me know.

By participating, you will be given a list of organizations/institutions in your community. They provide both health, psychosocial and legal services.

Do you agree to participate in this research?

1. ☐ Agree   2. ☐ Disagree

If **disagreed**, thank you for your time.

If **agreed**, thank you for your participation.

If you have answered "agree", you have read, or someone has read to you, information contained in this CD. You have had the opportunity to ask questions about the questionnaire and this stigma index project and been satisfied with the answers provided. Therefore, you agree to participate in this project on voluntary basis and you understand you can withdraw from this project at any time.

As such, I have provided my signature below to signify your agreement.

Signature/Initial of Interviewer

_____

Date of Interview _____

Your verbal agreement is crucial for the interview to proceed. If you are okay with the interview, please provide your signature or initial below to signify your consented participation.

Nevertheless, please be reminded that only the verbal consent is needed. You need not provide a written consent but can do so if you wish.

I have read, or someone has read to me, the information contained in the CD, inquired any information regarding this stigma index interview and been satisfied with the answers given. Thus, I declare my voluntary participation in this project and understand I can withdraw at any time.

Signature/Initial of Interviewee

_____

Date of Interview _____

Confidentiality Agreement – Research Team Leader

I, _____, leader of the research project on index of stigma and discrimination against HIV-positive people in _____ (insert country), agree to the following.

1. I will comply with all necessary measures in order to protect the information gathered through this project under my supervision. I will not disclose any information to anyone, either verbally or in writing, unless;

   a. By explicit directive of stakeholders involved in this project; or,
   b. By court order to disclose specific information.

2. I will comply with all requirements and measures to protect the information of the staff/volunteers according to relevant local law and regulations.
3. Any information stored in electronic format will be protected with a password or saved in an access-restricted file and I will ensure that only project staff/volunteer needing access to the information are given the password.
4. I will ensure that the interviewer conducting the data collection keeps "sensitive information" (list of contact and questionnaire numbers) in a safe place (i.e. locked) and that such information is kept separately from the questionnaires.
5. After the review and data input, I will destroy all the completed questionnaires and the "sensitive information". I will also instruct the interviewer to do the same. I will keep the contact information for notification of the results to the participating individuals only.
6. I will keep all information regarding identities of all individuals involved in this research secret and will not by any means disclose such information to anyone not involved in this project.
7. I will take responsibility to ensure the ethical compliance of this research. In training the researchers of this project, I will instruct them not to record any identity-related information in the questionnaire. I will delete (or make illegible) such information if found during the review of the completed questionnaires (i.e. quality inspection).

Research Team Leader

Signed,

Name (in clear handwriting)

Date

Place (province, country)

Witness

Signed,

Name (in clear handwriting)

Date

Place (province, country)

Confidentiality Agreement – Interviewer

I, _____, interviewer of the research
project on index of stigma and discrimination against HIV-positive people in
_____ (insert country), agree to the following.

1. I will comply with all necessary measures in order to protect the information I gather through this process and under this project. I will not disclose any information to anyone, either verbally or in writing, unless;

   a. By explicit directive of stakeholders involved in this project; or,
   b. By court order to disclose specific information.

2. I will not record information indicative of someone's identities in the questionnaire.
3. I will keep all information regarding identities of all individuals involved in this research secret and will not by any means disclose such information to anyone not involved in this project.
4. I will make sure to keep "sensitive information" (list of contact and questionnaire numbers) in a safe place (i.e. locked) and that such information is kept separately from the questionnaires.
5. Any information stored in electronic format will be protected with a password or saved in an access-restricted file to which only I have access.
6. After the review and data input and upon instruction from the team leader and _____ (insert organization supporting this research), I will destroy all the completed questionnaires and the "sensitive information". I will keep the contact information for notification of the results to the participating individuals only.

Interviewer

Signed,

Name (in clear handwriting)

Date

Place (province, country)

Team Leader or Witness

Signed,

Name (in clear handwriting)

Date

Place (province, country)

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