

HIV Stigma Index Report Timor-Leste



The first step toward change is awareness. The second step is acceptance.
- Nathaniel Branden, Canadian psychotherapist and writer

'.... there is still a lack of clear information to community and the reality is that discrimination still exists....' - HIV stigma index report participant

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Estrela+ is the national network for People Living with HIV (PLHIV) in Timor-Leste which works to improve the quality of the lives of all PLHIV in Timor-Leste through advocating for the recognition, respect and promotion of the rights of PLHIV at the local, national and international levels.

This report was written with the support and guidance of Courtney Wilson, Communications Mentor at Estrela+ (2016-2017).

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UNFPA, the United Nations Population Fund, is the UN agency for sexual and reproductive health and expands the possibilities for women and young people to lead healthy and productive lives. It is the lead UN agency for delivering a world where every pregnancy is wanted, every childbirth is safe and every young person's potential is fulfilled. Since UNFPA started working in 1969, there has been real progress - the number - and rate - of women dying from complications of pregnancy or childbirth has been halved. Families are smaller and healthier. Young people are more connected and empowered than ever before. Since 2003, UNFPA Timor-Leste has supported governmental and nongovernmental organizations' activities to address population issues and has strongly promoted reproductive rights and gender equality as key elements to achieve human rights and human dignity.



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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretrovirals
ART	Antiretroviral treatment/therapy
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
LGBTI	Lesbian Gay Bisexual Transgender and Intersex
MSTL	Marie Stopes Timor-Leste
NAPWHA	National Association of People with HIV Australia
PDHJ	The Ombudsman for Human Rights and Justice
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
SSpS	Missionary Sisters Servants of the Holy Spirit
UNFPA	United Nations Population Fund
UNHRAU	United Nations Human Rights Advisor Unit
WHO	World Health Organisation

Acknowledgements

This research is the result of extensive consultation and collaboration between Estrela+, people living with HIV in Timor-Leste, MSTL, GNP+, UNFPA and NAPWHA consultant, Dr John Rule. MSTL has been a valuable partner and support with Estrela+ to create, implement and understand this research work. UNFPA has been a pillar of technical advice and assistance to Estrela+ and have played a vital role in enumerator training and support throughout the research process.

It would not have been possible without the full participation and commitment of Estrela+ and people living with HIV. They identified the need for the project, lead the process, organised the interviews, conducted the interviews and reviewed the data.

The HIV stigma index steering committee also gave valuable guidance before the implementation of the index and throughout. Special thanks to the National Institute of Health for their approval and support of this research in Timor-Leste, as well as the Ministry of Health's national HIV programme.

A final thanks to all the participants who gave their time, shared their stories, and played an active and brave role in helping to address and stop stigma and discrimination in Timor-Leste for all people living with HIV.

The writing of this report was made possible with financial support received from UNFPA.

Foreword

Dr. Frederico Bosco Alves dos Santos
Former Head of the HIV/AIDS Program
Ministry of Health, Democratic Republic of Timor-Leste

Timor-Leste is committed to achieving the goal of universal access for prevention, treatment, and care for people living with HIV. This is in-line with the Constitution of Timor-Leste, which details the right of all people to access health care, including people living with HIV.

This is the first time the Stigma Index has been implemented in Timor-Leste. This research shows that people living with HIV still face many challenges in their daily lives and experience significant stigma and discrimination within their families, the health care sector and within communities at large.

This study also gives us greater understanding and guidance in how our responses to HIV should be focused and what needs to be done to eliminate stigma and discrimination, together.

The large multisectoral steering group committee involved in this study shows that there is an active and collaborative group of players in Timor-Leste who are committed to improving the health and well-being of people living with HIV. May their commitment be extended to implementing and advocating for the achievement of the recommendations in this report.

Signature:



Dr. Frederico Bosco Alves dos Santos,
Former Head of the HIV/AIDS Program
Ministry of Health, Democratic Republic of Timor-Leste

Executive summary

This study interviewed 81 people living with Human Immunodeficiency Virus (HIV) in Timor-Leste about their experience of stigma and discrimination in Timor-Leste from a range of backgrounds. Respondents ranged from 18 years old to 50 years and older, and were from Díli (46), Bobonaro (7), Covalima (4), Baucau (8), RAEOA (4), Manatuto (2), Ermera (4), Ainaro (1), Liquiçá (2), Lospalos (2) and Aileu (1). They had been diagnosed HIV positive for different lengths of time - from just over a year to more than 15 years. All wanted to be a part of a national conversation of how HIV is treated and discussed in Timor-Leste.

The HIV stigma index, developed by the Global Network of Positive People (GNP+), has been used as an instrument to research HIV-related stigma and discrimination in 90 countries around the world. This is the first piece of in-depth research on the experiences of PLWH in Timor-Leste. The numbers interviewed compared to the number of known diagnosis of HIV in Timor-Leste shows that information has been gathered from a significant proportion of those living with HIV in Timor-Leste.

Information was collected about age, education, family status, income level, profession and sexual orientation. Questions were also posed on the subjective reasons for stigmatisation and discrimination, including the reasons they might have happened associated with his or her HIV status. Finally, the research also investigated internal stigma and specific instances of stigma and discrimination associated with HIV status that occurred in the respondent's life within the past year, whether in connection with HIV testing, receiving medical or social assistance, access to work, healthcare services and education or the disclosure of confidential information about the respondent's HIV-positive status.

The research found that most of those interviewed had received education to at least primary school level and above. Many participants reported being in relationships and over half of them reported their health as currently being 'excellent' or 'good'. This information demonstrates that PLWH in Timor-Leste share the same socio-economic and demographic characteristics as the rest of the population and face the same concerns as people who do not have HIV. The problem, as outlined in this report, is that instances of HIV-related stigma and discrimination continue to occur in Timor-Leste, which has a negative impact on PLWH and add on to the many challenges they face.

These include:

- being tested without consent or without knowledge that they were having a HIV test,
- difficulty accessing regular medication and health services;
- experiencing verbal and physical abuse;
- having low self-esteem related to their HIV-status;
- receiving negative reactions from other people when they disclose their HIV status;
- unwanted disclosure of HIV status, including unwanted disclosure by healthcare workers, and;
- instances of coerced HIV testing and sterilisation (tubectomy).

In the qualitative section of this study, participants stated stock outs and expired ARV medication was a problem. This is despite Timor-Leste receiving international funding to procure and purchase ARV. Some respondents indicated that it was important for the government to regularly monitor the stock of medication and ensure that the right amount of medication is ordered, distributed and stored in the different health units providing ART.

More than a third of respondents (40%) said that a healthcare professional had told other people about their HIV status without their consent. It is international standard that disclosure should remain in the control of the person living with HIV. The study shows that this practice is not always followed in Timor-Leste. Only 40.74% of respondents reported making the decision to be tested for HIV independently. The other respondents were pressured by others or coerced into taking an HIV test without their knowledge.

'Lack of knowledge by the healthcare provider and the bias around access to sexual and reproductive health (SRH) services was another theme identified within this research. Four respondents (5%) said that they had been coerced into being sterilised (tubectomy) since being diagnosed as HIV-positive. Further, respondents reported being coerced by a health care professional to terminate a pregnancy (10.3% female respondents), about their method of giving birth (18% of female respondents) and around infant feeding practices (9% of female respondents). Respondents reporting coercion to terminate a pregnancy is concerning as abortions are highly restricted in Timor-Leste.

This research also discussed the management of pregnancies and prevention of mother-to-child transmission of HIV. Findings suggest that there has been inconsistent adherence to international guidelines, standards and recommendations regarding PMTCT in the country.

This study also highlights the importance of advocating for the rights and needs of PLWH and increasing understanding of HIV prevention, transmission and treatment in Timor-Leste. This shows the importance of continued support by national organisations and civil society to act as a voice for people living with HIV in Timor-Leste, both at the community level as well as at government and international level.

Recommendations based on these findings are suggested in the last section of the study as ways to decrease HIV-related stigma and discrimination in Timor-Leste, strengthen existing networks and programmes and opening pathways for people in Timor-Leste to access judgment-free HIV testing, treatment, care and support. Best practices for HIV prevention and management puts PLWH in the centre of the decision-making process and of projects and programmes targeting them.

Introduction

Background

In 2017 alone, 1.8 million people became newly infected with HIV and 940 000 people died from AIDS-related illnesses in the world. By the end of the year, there were 36.9 million people living with HIV worldwide. Out of those, only 21.7 million people were accessing antiretroviral therapy. East and Southern Africa accounts for the majority of new HIV infections in the world (800 000 in 2017), and have also the biggest number of people living with HIV (19.6 million) (UNAIDS, 2018).

Although not the hardest hit region, the Asia and the Pacific hold 9% of the total people living with HIV in the world, registering 280 000 new HIV infections in 2017. The majority of new infections are related to current or ex members of key population groups and their partner's network. The rising incidence of HIV among gay men and other men who have sex with men is worrisome in many countries of the region, and call for stronger HIV prevention interventions for this and other key populations. Even though some countries have made significant progresses in controlling the epidemic, the number of new HIV infections is still growing in countries like Pakistan or the Philippines (UNAIDS, 2018).

In neighbouring Indonesia, in 2017, there were 49 000 new HIV infections and 39 000 AIDS-related deaths. In total, there were 620 000 people living with HIV. Key populations are particularly hit by the infection, with percentages ranging from 5.3% among sex workers, to 25.8% among gay men and other men who have sex with men, and 28.8% among people who inject drugs (UNAIDS, 2018).

Timor-Leste Context

Timor-Leste is an island nation in South-East Asia, sharing a land border with Indonesia. It is a post-conflict state that in 2002 became the first new nation of the century. In 2003, the first case of HIV was diagnosed in Timor-Leste. The Ministry of Health (MoH) reports by end of 2017 there were 725 people living with HIV, out of which 287 were accessing antiretroviral treatment (Ministry of Health, 2017). Based on available numbers and evidence, Timor-Leste is described as having a low prevalence rate of HIV.

The relatively low prevalence rate (compared to other countries), contemporary international scientific knowledge and availability of appropriate medicines make Timor-Leste uniquely positioned to contain the spread of HIV if timely testing, treatment and retention in care can be improved.

There has been nevertheless an increase in the number of new HIV positive diagnoses over recent years. This increase provides a rationale for trying to understand the impact of stigma and discrimination on HIV testing rates, treatment and prevention in Timor-Leste. At the same time, the high number of STIs and Hepatitis B (WHO and Ministry of Health, 2017) might serve as a potential signifier, or proxy measure, indicating that HIV rates could also potentially increase.

In Timor-Leste, antiretroviral (ARV) treatment is provided free of charge at the National Hospital of Guido Valadares, five referral hospitals and Bairro-Pite Clinic. However, there are often difficulties for PLWH to access treatment. This includes travel constraints to the health units providing HIV

treatment or cases of stock out of ARVs. In 2015, only 65% of those diagnosed with HIV were on treatment, well below the UNAIDS 90-90-90 target (WHO and Ministry of Health, 2017). Furthermore, Prevention of Mother to Child Transmission of HIV (PMTCT) coverage was only 19.5 per cent in 2016 (WHO and Ministry of Health, 2017).

Understanding of HIV in Timor-Leste is very limited. The 2016 Timor-Leste Demographic and Health Survey (DHS) found that comprehensive knowledge about HIV prevention among young people had dropped from 12% to 8% for women and 20% to 15% for men. Furthermore, only 7% of women aged 15-49 and 26% of men aged 15-49 years knew where to get an HIV test, which helps explain why only 4% of the total population has ever been tested for HIV (GDS and ICF, 2017).

HIV-related stigma and discrimination has been identified as a barrier to HIV treatment in Timor-Leste. It prevents PLWH from having healthy and productive lives and it stops some from accessing testing and treatment. The current global approach to managing HIV transmission is called Treatment as Prevention (TASP). This approach can only be realised when HIV-related stigma and discrimination is reduced (Havlir and Breyer, 2012). In Timor-Leste, previous research shows cases of PLWH who have reported that the stigma and discrimination they face from healthcare workers has stopped them from attending treatment appointments (Williams, O'Haire and Nathan, 2017).

HIV prevention, human rights and dignity for people living with HIV

Reducing HIV-related stigma and discrimination is understood internationally as an important strategy in reducing HIV transmission (UNAIDS, 2014). From a human rights framework, it is only by eliminating HIV-related stigma and discrimination that PLWH will attain the highest level of health and well-being and be able to lead productive and happy lives.

National legislation protects the rights of people living with HIV in Timor-Leste. The constitution states: "Fundamental rights (...) shall not exclude any other rights provided for by the law and shall be interpreted in accordance with the Universal Declaration of Human Rights." (Government of Timor-Leste, 2002). The national labour law also protects the rights of people living with HIV to work in Timor-Leste without experiencing stigma and discrimination from their employer (Government of Timor-Leste, 2012).

Timor-Leste's response to HIV and AIDS is guided and supported by international guidelines and standards developed by UNAIDS, the World Health Organisation (WHO), the United Nations Population Fund (UNFPA) and The Global Fund, among others. Timor-Leste is a member state of the United Nations (UN) and as such is party to the Declaration on the Commitment of HIV/AIDS. This declaration of commitment on HIV/AIDS was a milestone document for the United Nations, where each member state recognised the global AIDS crisis and committed to measures that would slow the epidemic. The theme of this response was 'Global crisis, global action'.

Timor-Leste's government has also committed to the UNAIDS' 90:90:90 goal - treatment for all. UNAIDS' aim is that by 2020, 90 per cent of people living with HIV will know their HIV status; 90 per cent of all people diagnosed with HIV will be on antiretroviral treatment and 90 per cent of all people receiving antiretroviral treatment will have viral suppression (UNAIDS, October 2014).

Previous research about the experiences of people living with HIV in Timor-Leste

The first qualitative research on stigma and discrimination faced by people living with HIV in Timor-Leste was published in the Journal Culture, Health and Sexuality in January 2017, titled '*They say god punishes people with HIV: experiences of stigma and discrimination among adults with HIV in Dili, Timor-Leste*' (Williams et al, 2017). This research stated that "a profound lack of understanding about HIV transmission, cause of illness and potential for treatment among participants' families and communities, (...) appeared to contribute to the stigma people with HIV experienced". (2017,p.10). The study concluded that HIV-related stigma and discrimination required further research in Timor-Leste and Timor-Leste-specific interventions were needed: "The impact of stigma on the well-being of people with HIV who have experienced it is profound and warrants the introduction of evidence-based stigma reduction interventions that will be effective in Timor-Leste's unique social, economic and cultural context." (*ibid* p.12). HIV stigma index is being used in Timor-Leste to identify stigma and discrimination experienced by PLHIV and to inform leaders on the HIV-related programs.

Process and methodology using the global HIV stigma index in 2017

The purpose of this research was to gather information about the stigma, discrimination and rights of people living with HIV and determine the level of stigma they experience, through a participative process led by PLWH.

In April 2017, a steering committee was created with key partners and stakeholders working on, or with, HIV-related programmes to help develop and implement the research. These steering committee members included:

- Estrela+
- Esperança
- The Ministry of Health HIV programme
- The Ministry of Health Monitoring and Evaluation team
- The National AIDS Commission
- The Ministry of Health Key Population (KP) team
- The National Institute of Health (INS)
- The National University of Timor-Leste (UNTL)
- Marie Stopes Timor-Leste (MSTL)
- United Nations Population Fund (UNFPA)
- The United Nations Entity for Gender Equality and the Empowerment of Women (UN Women)
- World Health Organisation (WHO)
- RedeFeto
- Codiva
- Caritas-Dili
- Church World Service (CWS)
- The Ombudsman for Human Rights and Justice (PDHJ); and
- Sharis Haburas Comunidade (SHC).

The steering committee agreed that the Global HIV Stigma Index tool would be used in Timor-Leste to collect experiences of stigma and discrimination of people living with HIV. The objectives of the study were:

- 1) To obtain information about the situation and various events associated with HIV-related stigma and discrimination in the lives of people living with HIV in Timor-Leste;
- 2) Identify key barriers to HIV testing, prevention, treatment, care and support
- 3) To formulate recommendations on the necessary steps to fight the stigma and discrimination experienced by people living with HIV;
- 4) To provide an evidence base for improving services, policies and programmes related to people living with HIV in Timor-Leste.

Once the process had been agreed upon by the steering committee, the HIV Stigma Index was then translated into Tetun. It was further reviewed by the steering committee before being cognitively tested amongst a small group of people living with HIV. Ethical approval for the research was granted by the National Institute of Health in July 2017.

The enumerators used a questionnaire-based survey which involved people living with HIV as both respondents and interviewers. These enumerators received training prior to data collection. This included expert support from a trainer from the National Association of People with HIV Australia who had experience implementing the survey in other countries. Mentoring was also provided during the data collection period to ensure that all ethical agreements were followed and that data was being gathered and recorded accurately.

The main data-collection tool for determining the level of stigmatisation of people living with HIV was a questionnaire. The questionnaire consisted of three main sections:

Section 1 gathered general information about the respondent: age, education, family status, income level, profession and sexual orientation.

Section 2 identified subjective reasons for stigmatisation and discrimination and included questions about how the respondent viewed the reasons for stigmatisation and discrimination associated with his or her HIV status, as well as questions about internal stigma. This section of the questionnaire also includes questions about the respondents' awareness of their rights and existing laws and regulations governing the stigmatisation and discrimination associated with HIV status.

Section 3 collected information about stigma and discrimination associated with HIV status that occurred in the respondent's life within the past year, particularly in connection with HIV testing, receiving medical or social assistance, the respondent's access to work, healthcare services and education, or the disclosure of confidential information about the respondent's HIV-positive status. This section also included open-ended questions, which allowed those being interviewed to contribute information about their experiences living with HIV. These open-ended questions have been useful in generating a significant amount of qualitative information for further analysis.

Written informed consent was obtained by all participants in the study prior to the commencement of the questionnaire. If the participants could not sign their name, they used their fingerprint to give consent. Exclusion criteria meant that only individuals over 18 years of age and who had known their status for over 12 months could participate.

Data analysis was conducted by key members of the stigma index team, including enumerators. This was a participatory process, guided by and conducted by people living with HIV. The enumerators were also participants in the study.¹This participative process allowed the Greater Involvement of People with HIV/AIDS (GIPA) principle to be implemented throughout the research (UNAIDS, 2007).

¹Please contact Estrela+ at estrelaplus.easttimor@gmail.com for full details of the study methodology and tools used.

Findings

Demographics

A total of eighty-one respondents (thirty-nine females, thirty-eight males and four transgender) participated in the study². Six respondents identified themselves as men who have sex with men, one respondent as gay or lesbian, seven respondents as sex workers and two respondents identified themselves as an injecting drug user. Additionally, seven respondents identified themselves as a member of an indigenous group.

The majority of participants were aged between 25 and 39 years old (64.2%). There were nine participants aged between 15 to 24 years old. The remaining participants (24.69%) were aged over 40 years old. In the process of conducting the survey, a range of demographics which included gender, age, marginal and at-risk population groups were covered.

Over half of the respondents reported that they had known their HIV status for 1-4 years (56.79%). Twenty-five respondents reported that they had known their HIV status for 5-9 years and nine respondents said they had known for 10-14 years. One respondent reported knowing his/her HIV status for more than 15 years.

The majority of respondents were married and living with their partner (54.32%). Five respondents were in a relationship but not living with their partner and twenty respondents were single. Four of the respondents were divorced or separated and eight respondents were widows or widowers. Of those respondents in a relationship there was a varied response for how long they had been in a relationship (see Figure 1 below). Nearly 80% of the respondents were sexually active.

S1Q5 - If you are currently in a relationship, for how long have you been involved with your husband/wife/partner?

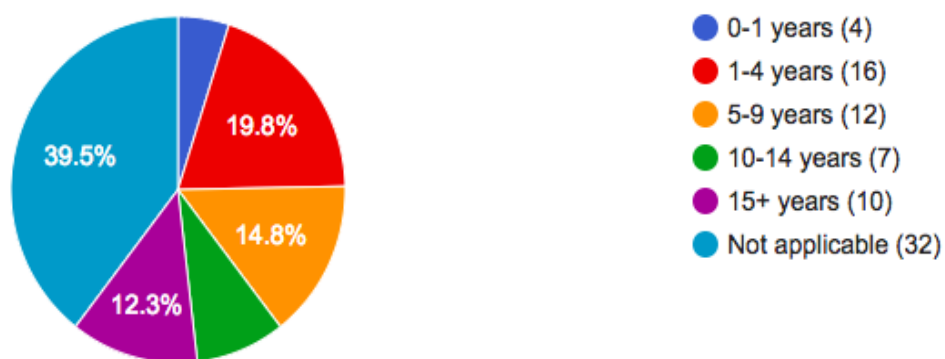


Figure 1: Years involved with partner

Eight respondents reported having a physical disability, including partial hearing impairment, partial vision impairment and loss of mobility.

The majority of respondents (65.43%) had completed secondary school or a technical college or university (see Figure 2). This is a higher level of education when compared to the general population: in Timor-Leste 50% of people are illiterate, 45% of men and 58% of women over 25

²There is an approximately 5.2:4.8 ratio of women: men diagnosed with HIV in Timor-Leste. MoH correspondence in 2018

years of age never went to school and 25% of men and 16% of women never finished secondary education (Ministry of Health, 2015).

S1Q9 - What is the highest level of formal education you have completed?



Figure 2: Highest level of education achieved

Thirty respondents said that they were in full-time employment, six respondents said they were in part-time employment, and ten respondents said they were working full-time, but self-employed. An additional ten respondents were doing casual or part-time work and twenty-five respondents were unemployed or not working at all. This is lower than the overall employment rate in Timor-Leste, which is reported at 52.6% (GDS, 2015).

Employment status	Number of respondents (n=81)	Percentage
Full-time work	30	37.04%
Part-time work	6	7.41%
Full time, self employed	10	12.35%
Casual or part-time work	10	12.35%
Unemployed	25	30.86%

Table 1: Respondents' employment status

Most respondents (61.73%) lived in a large town or city - predominantly Díli. Twenty-three respondents lived in a small town or village and eight respondents lived in a rural area. This demographic coverage indicates that a good representation of the HIV positive population in Timor-Leste was engaged in this research. Estrela+ was uniquely positioned to make contact with the diverse HIV positive population in Timor-Leste for the purpose of carrying out this study.

The respondents of this study and their experiences are indicative of the situation of people living with HIV in Timor-Leste. It is not representative of the whole population; however, it highlights areas of concern and is illustrative of the incidence of stigma and discrimination that the population has faced.

Seven key themes and nine sub-themes were developed from the analysis of the participants' answers and testimonies. Each theme will be analysed separately and, when possible, quotations will be used to better illustrate participants thoughts, feeling and opinions.

1. Personal stigma and discrimination

In strictly medical terms, there's no difference between HIV and diabetes; they're not curable, but they're very, very highly treatable, and early information is power. The only thing - literally the only thing - that is different is the stigma. And we have to overcome it, because it is now the only reason people are dying. - David Furnish – Chairman of the Elton John Aids Foundation (EJAF)

Respondents were asked what HIV-related stigma and discrimination they had experienced in the previous 12 months, such as social exclusion, abuse and manipulation. HIV-related stigma and discrimination are major barriers to prevention, treatment, care and support of PLWH (UNAIDS, 2014).

Respondents reported cases of social exclusion, gossip, verbal and physical abuse, discrimination in the workplace and denial of services. We will look at each one of these cases separately in the following sections of this report.

1.1. Exclusion

Three of the respondents reported that they had been excluded from social gatherings in the last 12 months (two of them were excluded often and one was excluded once) specifically because of their HIV status.

Six respondents reported that they had also been excluded from family activities such as cooking, eating together and sleeping in the same room because of their HIV status. Cases range from being excluded a few times, to being excluded often.

Comments about social exclusion include:

"I began finding more problems from discrimination through my wife's family and also my wife make discrimination through banning me from my own child and also my wife's father started separating my food through [different] eating plates and also cups."

"Without my consent, the health workers told my family of my HIV+ status before I could tell them and so I was subjected to stigma and discrimination from my family. Some members of my family have some understanding of HIV and some do not. Some members of my family do not want to be near me and they separate my things, clothes and plate and cups."

I have been staying with my aunty and uncle and I have gradually gotten better but they are scared that they will get HIV so they keep everything separate; we eat separately, I have separate plates and cups. My aunty always tells the neighbours that I have a really serious illness.

1.2. Gossip

The majority of the respondents (55.32%) had been gossiped about in the last 12 months at least once.³ Three of the respondents said they had been gossiped about once, 35 said they had been gossiped about a few times and six said they had been gossiped about often (see Figure 3). Nearly half of the respondents (41.77%) had experienced gossip because of their HIV status.

S2AQ4A - In the last 12 months, how often have you been aware of being gossiped about?

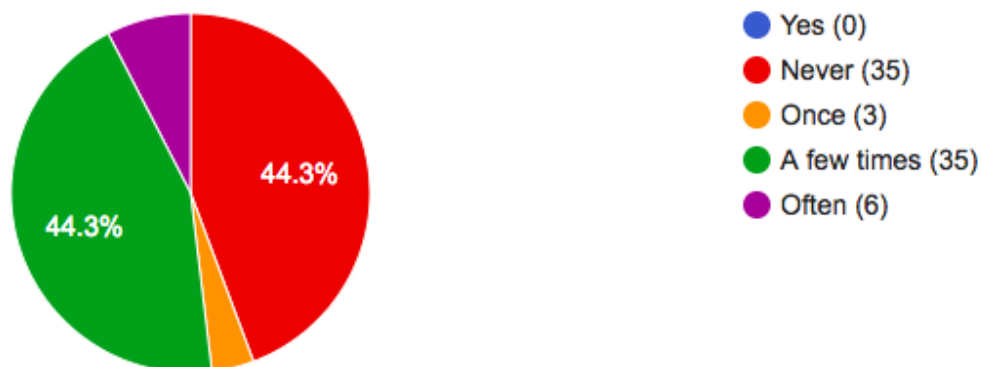


Figure 3: Percentage of respondents who experienced gossip

One of the respondents stated:

"I feel really scared sometimes because I experience stigma and discrimination from people because of my status. There is a really big problem with health workers keeping the status of patients confidential and also the family does not maintain the confidentiality and so there is a lot of gossip when you are open about your status."

1.3. Abuse

In the last 12 months, nineteen respondents reported being verbally insulted, harassed and/or threatened. Nine (11.1%) said that these episodes occurred once, five respondents (6.17%) said a few times and another five respondents (6.17%) said these happened often. Of the nineteen respondents that had experienced verbal abuse, 16 (84.21%) said that it was because of their HIV status.

Respondent's comments included:

"After my family knew my HIV status they really supported me; just only some friends and my neighbour don't like me and they abuse me and discriminate and they come into my house to threaten to hit me, and also try to inform my husband to not come and see me and my children."

"Sometimes my good friends told me that my other friends and community said that I am HIV infected. They like try to find out about my status, gossiping about me and insulting me indirectly but they never do it in front of me."

³There were only 79 responses to this question.

"I have a problem from my family: [they] always verbally threaten [me] and talk but I don't know who to ask for help."

Ten (12.35%) of the respondents had also experienced physical harassment and threats in the last 12 months. Six (7.41%) had experienced physical harassments and threats because of their HIV status, four (4.94%) said it was for another reason.

There were also reports of physical assault from eight (9.88%) respondents. Five of them said they were assaulted because of their HIV status and three said they were assaulted for another reason. All of these respondents reported being assaulted by people they knew: one (1.24%) was assaulted by their partner, four (4.94%) were assaulted by members of their household and three (3.70%) were assaulted by people outside of the household that were known to them.

"I divorced my husband because [my] husband's family said that I have a bad disease. So when my family heard that I am infected with HIV and divorced with my husband, my brother wanted to kill me and said I am not worthy to live and shamed me."

"Stigma and discrimination which is very strong for me is from my husband. Day and night he hits me, threatens me because of my HIV positive status and says I have a bad disease. He hits me to make me suffer so I follow his wants."

Other reasons for stigma and discrimination experienced by people living with HIV in the last 12 months included sexual orientation (3.67%) and being involved in sex work (6.7%).

Five respondents reported having been discriminated against by other people living with HIV, with four (4.94%) saying it happened a few times in the last 12 months.

The respondents were also asked to state why they thought they had experienced HIV-related stigma and discrimination in the last 12 months (if they had). Reasons mentioned included:

- People are afraid of getting infected with HIV from me (27.16%)
- People think that having HIV is shameful and they should not be associated with me (6.12%)
- Respondent was looking sick with symptoms associated with HIV/AIDS (2.47%).

At-risk groups and females were more likely to report HIV-related gossip, threats and abuse. Of those who reported having experienced verbal harassment, insults or threats, 74% were female, 16% were transgender (75% of transgender participants reported having experienced verbal harassment) and 11% were male.

Of those who reported having experienced physical assault, 90% were female and 10% were male. Furthermore, 90% of the participants who reported having experienced physical assault also experienced verbal harassment.

Respondents who identified as currently, or in the past, being a sex worker were more likely than others to experience gossip, verbal harassment, insults, threats, physical threats, harassment or

abuse. Two-thirds (66.67%) of the sex workers involved in the study had experienced gossip because of their HIV status. Furthermore, one-third experienced verbal and physical threats and abuse because of their HIV status. One instance of abuse was from a member of their household, and one was from somebody outside of the household. Five out of six (83.3%) of the respondents who identified themselves as sex workers said that they feared gossip because of their HIV status, and one-third (33.3%) feared verbal or physical harassment, insults, threats or physical abuse.

Wives, husbands and partners of the respondents were reported to also experience stigma and discrimination because of their spouse's HIV-positive status. Seven (8.64%) of the respondents said their partner had experienced discrimination a few times as a result of their status in the last 12 months. Four respondents (4.94%) said that their spouse had been discriminated against once in the last 12 months.

1.4. Employment

Four (4.94%) respondents reported that they had lost their job in the last 12 months: one respondent said it was a result of poor health and discrimination, while three reported that it was for other reasons. Two people (2.47%) said that they were refused employment or a work opportunity in the last 12 months because of their HIV status. One person (1.24%) reported that they had their job description or the nature of their work changed and/or refused a promotion because of their HIV status and a combination of discrimination and poor health.

"At that time, my spouse was running a small business at the school and people who knew my status went to that school together with the teachers, including the chief of the school, and the students [were] told to not buy the product or food that was sold by my spouse because it was contaminated with HIV virus."

"When [I] heard the result I felt scared and sad and had low self-esteem. I also found stigma and discrimination from work colleagues and I took the decision to stop working, and they changed my place to sit because they were scared with my HIV positive status."

1.5. Denial of services (for people living with HIV and their families)

One person reported that their child was dismissed, suspended or prevented from attending schools because of his/her parents HIV status. Another respondent said that they had been denied health services, including dental care because of their HIV status. Nearly a third of respondents (30.86%) had not accessed sexual and reproductive health services in the last 12 months. One person reported that they had been denied family planning services because of their HIV status. Furthermore, more than a third of the respondents (38.27%) had not been to family planning services in the last 12 months.

One respondent reported that family planning was recommended to her, but she did not want to follow this option.

"At the moment I had a blood test at national hospital, doctors forced me to follow family planning but I don't want to."

2. Internal stigma

"In stigma, a belief system is actually shared by the stigmatiser and the stigmatised. The stigmatiser fears becoming the type of person they hate, and the stigmatised person feels [that] shame... It's dependent on the stigmatised person actually giving a damn. Stigma has a grip on people: that's what's so toxic and unfair about it." - Yusef Azad (Cairns, 2013)

Internal stigma refers to how people living with HIV feel or think negatively due to their HIV status. In the study, the respondents were asked what were their feelings and thoughts related to their HIV status. Over half of the respondents reported having low self-esteem and feeling ashamed because of their HIV status, with 17.3% of respondents reported feeling suicidal (Table 2).

Table 2: Respondents' feelings and thoughts about themselves, because of their HIV status.

Feeling or thought reported	Percentage
Having low self-esteem	60.5%
Felt ashamed of their HIV status	53.1%
Blamed themselves	45.7%
Felt guilty of their HIV status	44.4%
Felt they should be punished	24.7%
Blame others	17.7%
Felt suicidal	17.3%

"When I disclosed to other people who are close to me, I feel I forced myself only because of the situation but then they know, slowly, slowly I begin to feel embarrassed and scared."

"The moment I knew my HIV result, I felt stressed, embarrassed, blamed myself, blamed others, had low self-esteem, felt as if punished, and felt my life was useless."

"At that time after the diagnosis I felt I didn't believe [it], depression, felt ashamed and scared and wanted to kill myself. Before I revealed my HIV status, some of my friends knew my HIV status and they also started to make stigma, [saying I] cannot be with them and this friend told my other friends and their partners (girlfriend/boyfriend) to not be near or around me."

Respondents were also asked if they acted in specific ways in the last 12 months because of their HIV status. One quarter of respondents reported that they decided not to have children, and over 10% reported the decision to not get married (Table 3).

Table 3: Actions taken by respondents due to internal stigma

Action	Number	Percentage
Decided not to have children	20	25% ⁴
Decided not to get married	10	12.5% ⁵
Avoided going to a local clinic	7	8.64%
Decided not to have sex	7	8.64%
Isolated themselves from family and friends	5	6.17%
Withdrew from education/training or did not take up an opportunity for education/training	4	4.94%
Avoided going to a local hospital	3	3.7%
Decided not to apply for a job, work or promotion	3	3.75% ⁶
Chose not to participate in social and community activities	1	1.24%
Made the decision to stop working	1	1.24%

The last section about internal stigma referred to whether people were fearful about being gossiped about, being verbally abused or being physically harassed or abused in the last 12 months. Nearly half of the participants were fearful of being gossiped about and almost 20% reported fear of verbal insult, harassment or threat.

When looking at gender specific responses, reported episodes of discrimination (gossip, verbal abuse and physical threats and abuse) were experienced differently. Female and transgender respondents were much more likely to fear experiencing gossip, threats and abuse than men respondents (Table 4).

Table 4: Fear of experiencing discrimination in the last 12 months due to HIV status

In the last 12 months, I have experienced...	Male	Female	Transgender	Total %
fear of being the subject of gossip	11 (28.95%)	20 (51.28%)	3 (75%)	43.2 %
fear of verbal insult, harassment or threat	3 (8.11%) ⁷	9 (23.68%) ⁸	1 (25%)	18.5%
fear of being physically harassed or threatened	0 (-)	6 (15.79%) ⁹	1 (25%)	9.9%
fear of physical assault	0 (-)	4 (10.53%) ¹⁰	1 (25%)	8.4%

Only four (6.4%) respondents were afraid that someone would not want to be sexually intimate with them because of their HIV status. However, fifteen (18.52%) respondents said that they had not disclosed their status to their partner.

⁴n=80

⁵n=80

⁶n=80

⁷n=37

⁸n=38

⁹n=38

¹⁰n=38

3. Understanding their rights as people living with HIV

Each of the respondents was asked what they knew about their international and national rights as a person living with HIV and if they had acted to protect their rights. More than half (67.9%) of the respondents had heard of the Declaration of Commitment on HIV/AIDS.¹¹ The declaration is an international document written and agreed upon by UN members to protect the rights of people living with HIV and actively be part of the solution to stop transmission of HIV. However, only 22 people had ever read or discussed the content of the Declaration (see Figure 4).

S2DQ1B - If yes, have you ever read or discussed the content of this Declaration?

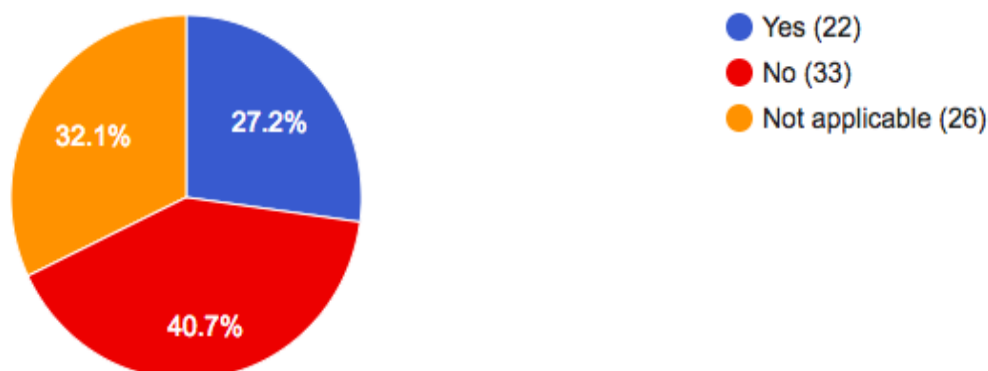


Figure 4: Percentage of respondents who have read or discussed the Declaration on the commitment to HIV/AIDS

The respondents were then asked if they had heard about the sections in the Timor-Leste constitution (Part II: Fundamental Rights, Duties, Liberties and Guarantees) and the Labour Code (see Annex 1) that protect people living with HIV in Timor-Leste.¹² More than half of the respondents (67.9%) had heard about these sections of the laws, however only twenty people (24.7%) had read or discussed the content of these laws (see Figure 5).

S2DQ2B - If yes, have you ever read or discussed the content of this [law/policy/set of guidelines]?

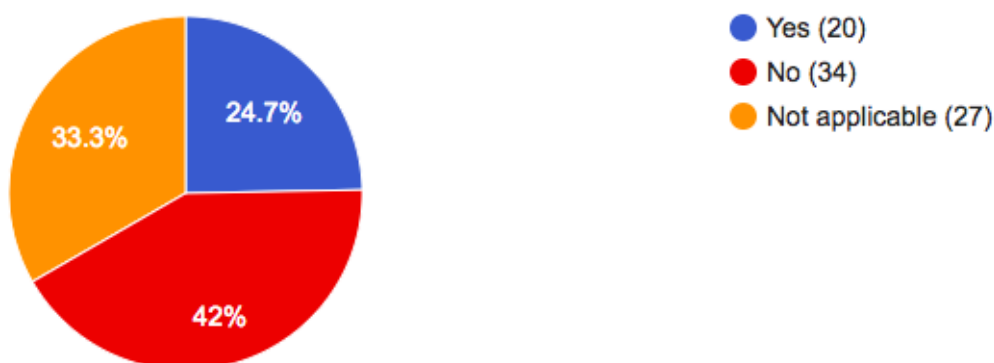


Figure 5: Percentage of respondents who have read or discussed the national laws protecting the rights of people living with HIV

¹¹This may be indicative of the number of respondents who are members of a national network for people living with HIV and the human rights overview provided to them as part of that network.

¹²Read Part II of the Timor-Leste Constitution here: http://timor-leste.gov.tl/wp-content/uploads/2010/03/Constitution_RDTL_ENG.pdf

The respondents were also asked if their rights had been abused in the last 12 months because of their HIV status. Seven respondents said they were forced to submit to a medical or health procedure, including HIV testing. One person reported being denied health insurance and two people reported being detained, quarantined, isolated or segregated (see Table 5).

Table 5: Abuse of rights experienced by people living with HIV

Abuse of rights of people living with HIV	Number of respondents	Percentage
None of these things happened	71	87.7%
Forced to submit to a medical or health procedure (including HIV testing)	7	8.6%
Detained, quarantined, isolated or segregated	2	2.5%
Denied health insurance or life insurance	1	1.24%
Arrested or taken to court on a charge related HIV status	0	-
Had to disclose status to enter another country	0	-
Had to disclose my HIV status to apply for residence or nationality	0	-

When the participants were asked if any of their rights had been abused, twelve people (14.8%) said yes and five people (6.2%) were unsure.

Five of these respondents had tried to get legal redress for this abuse, and four of these cases had begun in the last 12 months. Only one respondent's case had been dealt with, two were still waiting for the case to be addressed and two people said that the matter was not dealt with or nothing had happened.

One respondent described a situation where she was physically attacked by her brother. The case is currently being processed through the justice system.

"Problem which I face is from my husband's family not accepting my condition and me and my husband divorce; and one problem is my own brother not liking me because I must take medicine often. Because of this my brother wants to cut me with a machete. My brother cut my head and cut my hand. Until now it is not yet in good condition. My hand is wounded but my head started to be a little good now. The brother who cut me is now in [...] prison waiting processing."

Another respondent reported being treated in a violation of her rights by healthcare workers when she attended a medical check-up. She was tested for HIV, but was unaware of what a HIV positive result meant.

Before I had a test, I acquired a problem with my skin (itchy) and I went to the [community health centre] for a consultation. They asked me to take off all my clothes, and the nurse took a photo of my whole body (naked) – without clothes. During this moment I did not understand why they had asked me to take off all my clothes and lie down so they could take a photo (in this moment I feel my vagina a little itchy [STI problem]) and they asked a lot of questions like: are you sleeping with this man or other man and I responded that I was together with my beloved boyfriend and that they were forcing me to tell them about other men. I had only come so that they could give me some medicine.

But they took a blood test and they gave me the result in an envelope and they sent me to the hospital [...] where I had VCT [voluntary and confidential testing] and then after VCT they referred me to a skin doctor and then they give me Cotrim [an antibiotic]. After that they took blood and sent the test to Australia so they could assess my illness. I was told to come back after one week to get the result and VCT told me that I was positive and I thought that was good. They just told me to keep coming back for another two months so that they could take my blood test which they did two more times and then they told me that I was HIV+ and that I had to start the treatment of ART. They gave me an explanation of how to take medicine and to check/control every month and take the CD4 every six months.

Reasons for not following up on the abuse of their rights included:

- not having sufficient financial resources to take action (one person);
- the process of addressing the problem appeared too bureaucratic (two people);
- feeling intimidated or scared to take action (three people); and
- not having confidence that the outcome would be successful (three people).

No person reported being advised against taking action by someone else. However, the information above shows that those considering taking action had considerable barriers.

3.1. Confronting stigma and discrimination

The respondents were also asked if they had personally taken action if they had experienced stigma and discrimination. Twenty-two of the respondents (27.2%) had confronted, challenged or educated someone who was stigmatising and/or discriminating them.

The majority of respondents (90.1%) reported having knowledge of organisations or groups that help people who experience HIV-related stigma and discrimination. The known organisations or groups included HIV networks and support groups, government and non-government organisations (see Table 6).

Table 6: Respondent's knowledge of organisations or groups that support people living with HIV in Timor-Leste

Type of organisation	Number of respondents	Percentage of respondents	Examples
People living with HIV support group	56	69.14%	Esperança
Network of people living with HIV	43	53.09%	Estrela+
National AIDS council or committee	36	44.44%	CNCS-TL (the National AIDS Commission)
National non-governmental organisation	33	40.74%	Marie Stopes Timor-Leste, CODIVA
Faith-based organisation	20	24.69%	Caritas-Díli

Faith-based organisation	16	19.75%	Missionary Sisters Servants of the Holy Spirit - Becora
International non-governmental organisation	7	8.64%	World Health Organisation
A human rights organisation	6	7.41%	PDHJ
A legal practice	3	3.70%	
UN organisation	2	2.47%	UNFPA
Other	1	1.24%	PLHIV-Umbrella

Fourteen of the respondents (17.3%) had sought help from these organisations or groups to resolve an issue of stigma and discrimination. Furthermore, sixty-two of the respondents (76.5%) had supported other people living with HIV.

Examples include:

"I have had stigma and discrimination from my family. I went to the organisation Estrela+ and the organisation shared basic HIV information to the community, including my family.

"I informed Caritas Díli and the madres [at] SspS they helped collaborate with Estrela+ to resolve the problems that were taking place."

"I was mistreated by neighbour because of my HIV status and they refused to share clean water with me".

"I asked the nun to help me explain to my neighbour about this virus that I have and also to link me to my colleagues from Estrela+ to give me strength to face this (...) I was visited by them."

The majority of the respondents (80.2%) were currently a member of a support group and/or network of people living with HIV. In the last 12 months, thirty-nine respondents (48.8%) have been involved in a programme or project that provided assistance to people living with HIV. In addition to this, twenty-one people (25.9%) had been involved in efforts to develop legislation, policies or guidelines related to HIV.

Nevertheless, more than half the respondents (60.5%) reported that they didn't have the power to influence decisions relating to legal or rights matters affecting people living with HIV and local, national and international policies and programmes. (see Table 7).

Table 7: Perceived power of respondents to influence decisions relating to them

Power to influence decisions about...	Yes	No
None of the above	49 (60.5%)	32 (39.5%)
Legal/rights matters affecting people living with HIV	27 (33.3%)	54 (66.7%)
Local government policies affecting people living with HIV	11 (13.6%)	10 (86.4%)
National programmes/projects intended to benefit people living with HIV	11 (13.6%)	70 (86.4%)
Local projects intended to benefit people living with HIV	9 (11.1%)	72 (88.9%)
National government policies affecting people living with HIV	8 (9.9%)	73 (90.1%)
International agreements/treaties	3 (3.7%)	78 (96.3%)

When asked about the most important thing that should be done to address stigma and discrimination towards PLWH, most respondents (90%) mentioned the need for advocating for the rights of all people living with HIV. Other responses included: providing support to people living with HIV by providing emotional, physical and referral support (2.5%), advocating for the rights and/or providing support to particularly marginalised group (men who have sex with men, injecting drug users and sex workers) (1.24%), educating people living with HIV about living with HIV (including treatment literacy) (2.5%), raising the awareness and knowledge of the public about AIDS (3.75%). Only one person did not answer this question.

4. Testing

Respondents were asked why they were tested for HIV. They could choose more than one option. The most frequently reported reason for testing amongst respondents was being referred for testing due to suspected HIV-related symptoms followed by being tested when pregnant (See Table 8).

Table 8: Reasons for being tested for HIV

Reasons for being tested for HIV....	Number of respondents	% of Respondents
Referred by due to suspected HIV-related symptoms	26	32.1%
Tested when pregnant	13	16%
Because of the illness or the death of their spouse	11	13.6%
Were tested because they wanted to know.	9	11.1%
Employment	6	7.4%
Because their spouse or partner tested positive	6	7.4%
Referred by a clinic for sexually transmitted infections	2	2.5%

Other reasons included feeling sick and having a high fever, referrals from peer support groups and for a medical exam to apply for a scholarship. None were tested to prepare for a marriage/sexual relationship.

"When I was detected with HIV+ I was having treatment for TB and they (health service personnel) referred me for a HIV test. When they had the result they told me of my status and that I was positive. I did not have any pre-counselling because I was a TB patient and so I was not given it. I have never received clear information about the way HIV is transmitted."

Less than half (40.74%) of the respondents reported that the decision to be tested for HIV was made voluntarily. Five respondents (6.2%) said that they made the decision to be tested, but it was under pressure from others, twelve (14.8%) said that they were coerced into taking an HIV test and thirty-one (38.3%) reported being tested for HIV without their knowledge. They only found out after the test had been done (see Figure 6).

S3AQ2 - Was the decision to be tested for HIV up to you?



Figure 6: Who made the decision for respondents to have an HIV test

Personal experiences of the respondents include:

"The problem with having a test for HIV was that it was obligatory and I did not have counselling and did not have confidentiality from health care workers when the result was positive. And I was not prepared myself and not ready to receive a positive HIV result"

"When I first tested, the result was not given to me directly and at the moment I did not know that I was being tested for HIV and that I had HIV symptoms as well as I was pregnant."

"I didn't know when I was having the test for HIV and when I received ARV treatment I also didn't know yet that I was HIV positive. It was only after already receiving ARV treatment for 3 or 4 days that I knew I am positive with HIV."

The respondents were also asked if they received pre- and post-test counselling when they were tested for HIV.¹³ More than half (54.3%) said that they received both pre- and post-test counselling, one respondent said that they received only pre-test counselling, eighteen said that they received only post-test counselling and another eighteen said that they did not receive any counselling when they had an HIV test.

"When I had the test I didn't know or did not get pre- and post- test counselling. After the test I heard that I was affected with HIV and first I was amazed because I didn't know the doctors had tested me for HIV."

Pre- and post-test counselling is important for understanding HIV transmission, prevention, treatment and care and support. One of the respondent's husband was diagnosed HIV positive, and because she was unaware on how to prevent transmission, she later also became HIV positive.

"When I first had a blood test I was confused about what I can do. In my mind I think that only sick people have their blood tested, but why if my condition is good like now, why do I have to have a blood test? At the time, from health provider [...], they told me that they need to take my blood to only look if I get some disease, but I told them that my husband is sick so why test my blood?"

¹³Pre-test counselling was only introduced in Timor-Leste as part of the HIV testing in 2006. Therefore, respondents who were tested before 2006 were not offered pre-test counselling.

This happened in 2005. Two days after taking my blood I go to ask the result in the VCT and then the VCT informed to me that my husband is detected with this virus and I am not. And the VCT told me that I need to prevent, and I don't know how to prevent it."

5. Treatment

The respondents were asked about their general health when they participated in the survey, with eighteen (22.2%) saying their health was excellent, twenty-seven (33.3%) saying it was very good, thirty-one (38.3%) considering it was good and five (6.2%) fair. None of the respondents said that their health was poor (see Figure 7).

S3CQ1 - In general, how would you describe your health at the moment?

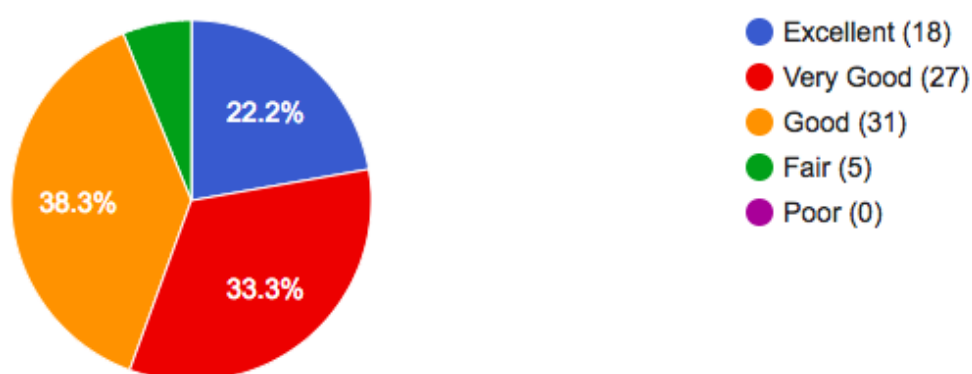


Figure 7: Reported health of respondents

Seventy-seven (95.1%) of the respondents reported taking antiretroviral treatment, but four of them (4.9%) said they were not, despite three of those respondents saying that they had access to antiretroviral treatment. Out of the four participants not on ART, three were men and one was a woman. Reasons for not taking antiretroviral treatment included lack of transportation, absence of symptoms (feeling good at the moment) not having access to antiretroviral treatment.

"Until now, for two years, I do not go to have treatment and I do not take medicine because currently my body is good."

"Treatment stopped in 2013 because there was no medicine (...). In 2016 I continued treatment at Bairro-Pité Clinic."

"Currently I do not yet take ARV medication because I still feel OK, CD4 is high."

"Currently I am not taking ARV. The reason is because I live far from the treatment place. I don't have transport."

In the last 12 months, seventy-one (87.7%) respondents said that they had a constructive discussion with a healthcare professional about HIV-related treatment options, while ten (12.3%) had not had such a discussion with their healthcare professional.

Forty respondents (49.4%) also said they talked about other subjects with their health care professional, such as their sexual and reproductive health, sexual relationship(s) emotional well-being and drug use. The other half of the respondents (forty-one) said that they had not.

Other issues reported by respondents about HIV treatment were its strong side effects, such as dizziness, feeling faint, nausea, itchiness, rashes and bad dreams; stock outs of specific antiretroviral medication; expired medications and distance to the treatment centre.

"There is a lot of expired ARV. The government really needs to pay attention for those that are on treatment and the services for those that are on treatment for the future."

The distance of the respondent's home to the treatment centre was a barrier to treatment for some respondents as they did not have transport options to go to the treatment centres.

"The problem for me is that sometimes I stop ART because the distance to go for the medicine is far and I do not have transportation to support me."

"Currently I take medicine in Baucau. This is a preoccupation for me because of the long distance from my house. But healthcare workers also support me when my medicine finishes: they always remember to contact me."

"Currently, I (...) always take medicine each month, unless the distance of where I stay is far from the hospital, because I must walk from mountain just to catch the car to go take the medicine. Now I live in a rural area."

6. Having children

More than two-thirds of the respondents had children (70.4%). Since being diagnosed as HIV-positive, forty-six of the respondents (56.8%) said that they had received counselling about their reproductive options, but twenty-two (27.2%) said they did not. Thirteen (16%) found this was not applicable to them.

One respondent reported that healthcare workers would not operate on her due to her HIV status.

"I had a problem with stigma and discrimination when I was pregnant and had a caesarean but doctors from [hospital] would not receive me to have a caesarean operation because of my HIV status."

Fourteen of the respondents (17.3%) reported that their healthcare professional had advised them not to have a child since being diagnosed as HIV-positive:

" [There was a] problem with the doctor and nurse telling me not to have children."

"I have problem because when I gave birth the healthcare workers banned [me] from being able to have children again during [my] life and said I must follow contraceptives such as pill."

"Medical professionals and nurses banned me from having more children."

Four respondents (5%) said that they had been coerced into being sterilised (tubectomy) since being diagnosed as HIV-positive.

Female respondents were also asked if they had been coerced by a healthcare professional to have a termination of pregnancy, about the method of giving birth and infant feeding practices (see Table 9).

Table 9: Respondent-reported experience of coercion by health care professionals (female respondents only)

Coerced into...	Yes	No	Not applicable
Termination of pregnancy (abortion) (n = 39)	4 (10.3%)	27(69.2%)	8 (20.5%)
Method of giving birth (n = 34)	6 (17.6%)	25 (73.5%)	3 (8.8%)
Infant feeding practices (n = 34)	3 (8.8%)	28 (82.4%)	3 (8.8%)

The female respondents who had children (n = 34) were also asked if they had ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy. Nineteen (55.9%) said that they had received such treatment while ten respondents (29.4%) did not have access to such treatment. Six respondents (17.6%) said they were not HIV-positive when they were pregnant.

All of the nineteen respondents who reported being given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy were also given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to-child transmission of HIV.

"Connection to having children, yes I had the test. After the final test [I] find treatment immediately and also find information about prevention to my baby during pregnancy, after the birth and I breastfeed until one year. Now have stopped breastfeeding but my child test result is HIV negative twice and condition is good."

"When I am detected HIV positive I am five months pregnant and I immediately have treatment to have prevention for baby and until now baby not have problem because when born found immediately prophylaxis from medics."

7. Disclosure

The respondents were also asked how their HIV status was first disclosed to specific people or groups - if their status had been disclosed. Other than health care professionals, respondents were most likely to tell other people living with HIV about their status (44.3%), followed by their partners (34.2%) and adult family members (24%).

The support of partners and other people living with HIV was important for respondents (see Figures 8-17 for more information about disclosure of HIV status). However, 24 of the respondents' partners were told without PLWH's consent. Reports from the qualitative data indicate that disclosure without consent was often carried out by healthcare professionals.

"My main problem (...) is that I did not yet give out my HIV status to other people or in my home. Health personnel inform first my wife. Following this my wife and my household really support me but then after four or five months they start to discriminate me."

"When I was first tested, the result was not given to me directly and at the moment I did not know that I was tested for HIV (...) After the test was done, from the health facility site they informed directly to my husband, parents and myself. When I saw my status as HIV+ in the hospital room in which I stayed, I was confused until my husband explained it to me and asked me if I have had blood transfusion before when I was still single or if I had contacted with other people's blood or not?"

"Her husband was sick and in the hospital they did a HIV test. Then all the doctors wrote her husband's HIV status and put at the end of the bed. She also heard and saw her husband's status and heard that this HIV is a bad disease. She went directly to ask doctor and the doctor responded that this disease was a dangerous disease and that there was no medicine unless at Bairro-Pité Clinic. Her husband heard and ran away from the hospital."

Table 10 shows how key groups and individuals were told about the HIV status of the respondent, if they had been told. For these questions, 'Not applicable' means that the respondent felt the question was not relevant to their situation. For example, 'Not applicable' for method of disclosure to a partner includes people that did not have a husband/wife/partner.

Table 10: Disclosure of HIV status – how people and groups of people were first told about the respondent's HIV status.¹⁴

People or groups of people	How they were told about the respondent's HIV status	Percentage
Method of disclosure to partner (husband/wife/partner)	I told them	34.5%
	Someone else told them WITH my consent	22.5%
	Someone else told them WITHOUT my consent	21.5%
	They don't know my HIV status	13.5%
	Not applicable	8%
Method of disclosure to adult family members	They don't know my HIV status	34.6%
	Someone else told them WITHOUT my consent	28.6%
	I told them	24%
	Someone else told them WITH my consent	8%
	Not applicable	4.8%
Method of disclosure to child family members	They don't know my HIV status	65.2%
	Not applicable	13.5%
	Someone else told them WITHOUT my consent	9%
	I told them	9%
	Someone else told them WITH my consent	3.3%
Method of disclosure to friends	They don't know my HIV status	38.7%
	Not applicable	25.8%
	Someone else told them WITHOUT my consent	17.2%
	I told them	14%

¹⁴As reported to the enumerator by respondents.

	Someone else told them WITH my consent	4.3%
Method of disclosure to other people living with HIV	I told them	44.3%
	Someone else told them WITHOUT my consent	30%
	Someone else told them WITH my consent	22.9%
	They don't know my HIV status	1.4%
	Not applicable	1.4%
Method of disclosure to co-workers	Not applicable	45.7%
	I told them	22.3%
	They don't know my HIV status	17%
	Someone else told them WITHOUT my consent	7.6%
	Someone else told them WITH my consent	7.4%
Method of disclosure to employers	Not applicable	64.3%
	I told them	13.1%
	They don't know my HIV status	9.2%
	Someone else told them WITHOUT my consent	8.1%
	Someone else told them with my consent	5.3%
Method of disclosure to religious leaders	Not applicable	33%
	I told them	22%
	Someone else told them WITHOUT my consent	17.4%
	Someone else told them WITH my consent	17.4%
	They don't know my HIV status	10.2%
Method of disclosure to health care workers	Someone else told them WITHOUT my consent	51.7%
	I told them	24.1%
	Someone else them WITH my consent	19%
	They don't know my HIV status	4%
	Not applicable	1.2%
Method of disclosure to counsellor	Someone else told them WITHOUT my consent	40.5%
	I told them	25.9%
	Someone else told them WITH my consent	24.1%
	Not applicable	7.7%
	They don't know my HIV status	1.7%

7.1. Reactions of individuals following disclosure

Overall, other people living with HIV and partners of people living with HIV were most likely to be reported as being very supportive when they were first told about respondents' HIV status. When partners were told of the respondent's HIV status:¹⁵

- Thirty-seven (45.7%) were very supportive,
- Seven (8.64%) were supportive,
- Eight (9.88%) reacted no differently to before the disclosure,
- Two (2.47%) were discriminatory; and
- Two (2.47%) were very discriminatory.

¹⁵As reported to the enumerators by respondents.

Table 11: Reaction of people and groups when they first heard about a respondent's HIV status¹⁶

People or groups of people	How they reacted to hearing about the respondent's HIV status	Percentage
Reaction of partner (husband/wife/partner)	Very Supportive	45.7%
	Supportive	8.6%
	No Different	9.9%
	Discriminatory	2.5%
	Very Discriminatory	2.5%
	Not applicable	30.8%
Reaction of adult family members	Very Supportive	16%
	Supportive	8.6%
	No Different	13.6%
	Discriminatory	8.7%
	Very Discriminatory	3.7%
	Not applicable	49.4%
Reaction of health care workers	Very Supportive	29.6%
	Supportive	46.9%
	No Different	11.1%
	Discriminatory	3.7%
	Very Discriminatory	3.7%
	Not applicable	4.9%
Reaction of counsellors	Very Supportive	40.7%
	Supportive	45.7%
	No Different	1.3%
	Discriminatory	1.3%
	Very Discriminatory	1.3%
	Not applicable	9.8%

The respondents had mixed experiences when disclosing their status. Twenty respondents had not disclosed their status to anyone. Of the respondents that had, twenty-nine (35.8%) found it an empowering experience. However, thirty-two (39.5%) did not.

Some participants reported that when they first disclosed their status to others, they experienced stigma and discrimination. However, as their friends and family learned more about HIV, stigma and discrimination decreased.

Another respondent had provided her family with basic HIV information about how HIV is transmitted and treated to decrease HIV-related stigma and discrimination. She decided to do this herself as she was unaware of support groups or people that could help her.

¹⁶As reported to the enumerators by respondents.

"I tried to resolve the issue of stigma and discrimination which happened to me by myself by sharing basic HIV information with my family and they understood and did not make more stigma and discrimination to me."

Respondents reported that lack of understanding about HIV and AIDS by their friends, family and community led to stigma and discrimination following disclosure. However, once friends, families and the community learned more about HIV treatment, prevention, care and support, they were more accepting and understanding of the person living with HIV.

"(...) people do not understand the situation for people living with HIV. I feel people talk behind my back only based on incorrect information from the media."

"The first time that I found stigma and discrimination was from my own family, because they do not have a deep understanding [about HIV]."

7.2. Pressure to disclose

Respondents were also asked how often they felt pressure from other individuals living with HIV or from other groups/networks of people living with HIV to disclose their status. Most of the respondents (75 or 92.6%) said this situation never happened, but there were cases (6 or 7.4%) when respondents felt they had been pressured to disclose their HIV status.

The same situation was reported regarding pressure to disclose by other individuals not living with HIV (e.g. family members, social workers, employees of non-governmental organisations) One respondent (1.24%) said often, seven respondents (8.8%) said a few times and seventy-two respondents (90%) said never.

7.3. Disclosure of status by health care professionals

More than a third of respondents said that a healthcare professional (for example a doctor, nurse, counsellor or laboratory technician) had told other people about their HIV status without their consent. A third of respondents were not sure if their status had been disclosed. Just less than a third of the respondents had not had their status disclosed (see Figure 8).

S3BQ3 - Has a health care professional (for example, a doctor, nurse, counsellor, laboratory technician) ever told other people about your HIV status without your consent?

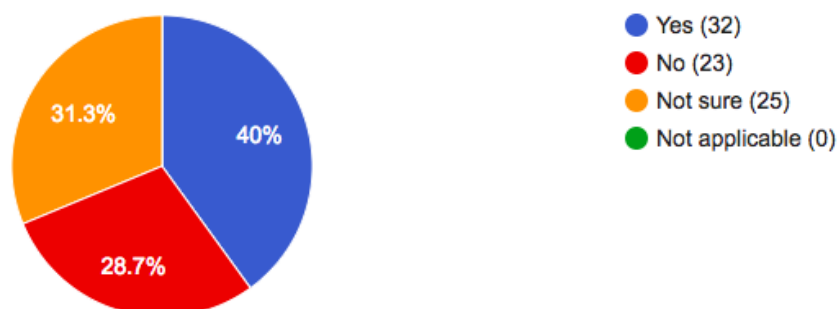


Figure 8: Disclosure of HIV status by health care professionals

Respondents reported:

"I feel unsafe because [I am] scared other people make stigma and discrimination to me and many people not yet know HIV information. [We] need to increase the community understanding about how to reduce stigma and discrimination. I feel that health personnel do not yet keep well people's confidentiality (...). Many times they say that HIV is a 'bad disease'. "

"[I] don't believe my status will be kept confidential by healthcare workers and especially by laboratory technicians."

"I do not believe [I should disclose my status] and I don't believe that my status will be confidential in the laboratory."

Despite this, 37 respondents (46.3%) said that they were sure that their medical records would be kept completely confidential. Thirty-five participants (43.8%) were unsure about this but eight people (10%) said that it was clear that their medical records were not being kept completely confidential.

Limitations and challenges of the study

This is the first time the HIV Stigma Index has been conducted in Timor-Leste. Some limitations and challenges to note from this research work include:

- All of the findings are self-reported
- There were some difficulties in understanding of questions about disclosure and stigma. The enumerator did their best to explain what was meant by each question.
- There were some barriers around the local language used. The enumerators were helped by the translator during the interview.
- This is qualitative research and should be part of the evidence base of HIV-related stigma and discrimination; however the population size was too small to extrapolate definitive data. It is indicative of trends and issues.

Recommendations

This study highlights a number of issues facing people living with HIV in Timor-Leste, including experiences of stigma and discrimination from family, community and healthcare workers. The findings of this report suggest to the government, religious leaders and private institutions that changes need to occur in HIV-related messaging, projects and programmes in Timor-Leste to decrease HIV-related stigma and discrimination in Timor-Leste and improve HIV testing, treatment and prevention.

People living with HIV in Timor-Leste

Currently, HIV programmes and messaging are focused on the most at-risk populations – MARPs or key populations (men who have sex with men, transgender persons, sex workers and their clients or injecting drug users). The findings that the majority of people living with HIV interviewed in this study were married or cohabitating with their partners, and that only sixteen respondents (19.75%) identified themselves as a member a key population [2] is of interest as it suggests that the HIV epidemic in Timor-Leste might be expanding to the general population and not necessarily concentrated in members of the MARPs.

Internal stigma

Respondents reported experiencing internal stigma and negative thoughts at the time of diagnosis and in the last 12 months. It is important to provide good counselling and support after testing through counsellors and peer support.

Many of the respondents reported feeling more positive after understanding more about HIV and talking to other people living with HIV. Decreasing both internal stigma and HIV-related stigma in Timor-Leste through peer support and HIV messaging that focuses on changing negative attitudes towards HIV is important to increase the overall well-being of people living with HIV and to decrease barriers to testing.

Disclosure

The support of partners and people living with HIV was important for respondents. This highlights the importance of networks of people living with HIV and support groups in Timor-Leste. More training should be provided to healthcare professionals about the options of support groups available in their area and referral pathways, including support for partners of people living with HIV.

The findings also indicate that non-disclosure occurs because respondents fear stigma and discrimination after disclosure. UNAIDS states that fear of non-disclosure due to a fear of stigma and discrimination can discourage “people living with HIV from disclosing their status even to family members and sexual partners and undermines their ability and willingness to access and adhere to treatment.” (UNAIDS, 2014). For people living with HIV in Timor-Leste, unwanted disclosure of their HIV status is occurring in a range of settings and one of the strong recommendations of this report is that correct community education about HIV is needed to prevent unwanted disclosure occurring. When diagnosed in a timely manner, with access to optimal treatment and care, HIV is a chronic manageable illness.

It is an international principle that disclosure should remain in the control of the person living with HIV. Unfortunately the study reveals this is not happening in Timor-Leste.

Unwanted disclosure must be addressed through community and healthcare worker education if the epidemic is to be controlled. It is recommended that people living with HIV need support and education to be empowered and manage those instances when their status is disclosed without their consent.

Lack of confidentiality of healthcare professionals

Lack of confidentiality among healthcare workers in Timor-Leste was identified as a problem experienced by many people living with HIV. There were reports of healthcare workers disclosing respondents' HIV status to partners, friends and family before they told the respondent themselves.

When the rights of people living with HIV are not respected, this impacts on HIV/AIDS prevention, treatment, care and support. It also limits efforts to decrease risk of transmission. This is the same for prevention and testing, as prevention efforts are limited when people do not want to have testing because they are scared to know if they are HIV positive.

It is important to include regular HIV-specific training for healthcare workers to ensure that they are aware of the importance of confidentiality, HIV treatment and adherence, modes of transmission and the referral pathways to care and support organizations, such as Estrela+.

Stigma and discrimination from healthcare workers

Another issue identified in the study was stigma and discrimination from healthcare workers. Even though the HIV stigma index did not ask directly about stigma and discrimination experienced from healthcare workers, the qualitative reports of unwanted disclosure by healthcare workers and stigma and discrimination perpetrated by them is a concern.

Within the healthcare setting, lack of knowledge about HIV and provider bias around family planning was also found to be a great concern. Even though lack of confidentiality by healthcare workers was recognised as a problem, the majority of respondents (75.6%) said that healthcare workers were supportive or very supportive when they first heard about their HIV status. Further monitoring and evaluation of the support given by healthcare workers is thus needed.

There was also a lack of understanding about HIV and AIDS by respondents themselves. This negatively affects adherence to treatment and prevention. The overwhelming respondents (88.9% of respondents) answered that they think the most important thing is advocating for the rights of all people living with HIV. This shows the importance of continued support of national organisations, such as Estrela+, to act as a voice for people living with HIV in Timor-Leste both at the community level as well as the government and international level.

Access to medication

In the qualitative section of the questionnaire, respondents were asked what problems and challenges they had faced regarding antiretroviral treatment. There were reports of stock outs, expired medication, bad side effects and the long distance to the treatment centre. Whilst medications are theoretically available free of charge, information from respondents demonstrates that medication is not always accessible, and in fact not always available.

Stock outs and expired medications should not occur in Timor-Leste and should be appropriately managed. Ordering of antiretrovirals occurs through the Ministry of Health national HIV programme. An audit of the national ordering system and how it is regulated should be performed in light of reports of stock outs and expired medications.

At-risk groups and gender-related stigma and discrimination

The finding that transgender people, women and sex workers are more likely to experience HIV-related gossip, verbal or physical harassment, insults and threats indicates the importance of ensuring that LGBTI communities in Timor-Leste receive HIV-related information about prevention, treatment, care and support to decrease their risk of HIV and HIV-related stigma and discrimination.

Sex workers also reported higher rates of gossip, verbal and physical harassment, threats or insults and physical abuse. There is currently no national network or organisation advocating for the rights and needs of sex workers in Timor-Leste and promoting the importance of HIV prevention. This issue needs to be further explored and specific programmes should be created to protect the rights and decrease HIV-related stigma and discrimination of sex workers in Timor-Leste.

Use of family planning services

Nearly a third of respondents (30.86%) had not accessed sexual and reproductive health services in the last 12 months. This is a trend in the general population as well. Overall, unmet need for family planning services in Timor-Leste dropped from 32% in 2009-10 to 25% in 2016 (GDS and ICF, 2017, p13). However, only 26% of women are using a method of family planning: 24% using modern methods and 2% using traditional methods. In addition, modern contraceptive use has increased from 21% in 2009/10 to 24% in 2016 (GDS and ICF, 2017, 11).

A change in family planning use has also been observed between the 2009/10 DHS and 2016 DHS, with an increasingly diverse method mix in married women aged 15 – 49. This is shown through increased uptake of the contraceptive implant (0.8% in the 2009/10 DHS to 6.2% in the 2016 DHS) and decreased uptake of injectable contraceptives (15.7% in 2009/10 to 11.7% in 2016 DHS).

The importance of looking at contraceptive method mix is that it indicates if a population has access to a wide range of methods and can provide indication on user preference or provider bias in method provision (Measure Evaluation, 2017). A more diverse method mix, as shown in the 2016 DHS, suggests increased access to comprehensive family planning services in Timor-Leste at a national level.

Despite these improvements at a national level, this study indicates that people living with HIV face discrimination and provider bias in family planning counselling and service provision. Four respondents reported being coerced into being sterilised (tubectomy) which call for an extra step of comprehensive, non-judgemental counselling to ensure people have not been coerced.

Respondents reported being coerced into the termination of pregnancy is also concerning as it is a highly restricted service in Timor-Leste. These findings warrant further research for community and provider perceptions, understanding and experiences around the termination of pregnancy in Timor-Leste.

HIV testing

The decision to be tested for HIV was only made voluntarily and purposefully by 33 of the respondents (40.74%). Other respondents had an HIV test without their knowledge, were pressured by others to take the test or were coerced by others. One respondent reported that he did not know he had an HIV test, and had been taking antiretrovirals for three to four days before he was told that he was HIV positive. This is a concerning finding of this study and further investigation needs to occur about the patient – provider relationship and provision of pre and post-test counselling.

Specific findings and recommendations can be found in a table as an Annex of this report.

Conclusion

This formative research around stigma and discrimination experienced by people living with HIV in Timor-Leste demonstrates that significant challenges exist around social inclusion, access to comprehensive information, quality HIV-related services and non-judgemental health care. This includes barriers to HIV testing and treatment, such as lack of understanding about HIV and fear of disclosure from healthcare workers. These issues need to be addressed in Timor-Leste to lead the way for improved testing and adherence to treatment.

The success of conducting this research and writing this report – led and implemented by people living with HIV – demonstrates the power and ability of this community to understand and advocate for their rights. However, they alone are not able to implement the recommendations detailed in this report. Stigma and discrimination have a profound effect on people living with HIV in Timor-Leste and the recommendations in this report should be adopted and included in HIV-related projects and programmes in the country.

Eliminating stigma and discrimination towards people living with HIV within communities, the workforce and health sector requires the support and actions from everyone. These actions should always be guided and inclusive of people living with HIV to ensure they are non-discriminatory and impactful. This study provides an evidence base on which to build actions and recommendations from that should be implemented to ensure that the rights and needs of people living with HIV in Timor-Leste are upheld and respected, so they can live healthy and productive lives.

Recommended actions

Findings	Recommended action
HIV cases in Timor-Leste are not only limited to key populations, but also present in the general population	Ministry of Health should collaborate with the National AIDS Commission and civil society, including Estrela+, to disseminate evidence-based HIV related information about HIV transmission, prevention, testing, treatment and care and support to PLWH. This intervention should target the general public in Timor-Leste through a coordinated public health campaign led by PLWH and the HIV Programmed of Ministry of Health.
People living with HIV in Timor-Leste experience internal stigma	The Government of Timor-Leste with the Ministry of Health should provide support to civil society organizations who deliver services to PLWH to enhance counselling and support after testing through counsellors and peer support in order to decrease internal stigma. Ministry of Health should support civil society organizations to strengthen their peer education and support network in Timor-Leste. Timor-Leste National AIDS Commission should collaborate with Ministry of Health and civil society organizations to develop correct and evidence-based HIV education and information materials, in particular for immediate family and friends, about HIV in Timor-Leste and how to support newly-diagnosed patients.
Lack of confidentiality of patients' HIV status by healthcare personnel	Ministry of Health should work together with civil society organizations who deal with HIV related stigma and discrimination to sensitize healthcare personnel in Timor-Leste to treat patients with respect and dignity, and on the obligation to adhere to a medical code of ethics that includes confidentiality of test results.
Stigma and discrimination from healthcare personnel towards people living with HIV	Ministry of Health should ensure specific trainings on HIV stigma and discrimination are included on regular trainings for health personnel to ensure they are aware of the importance of confidentiality, HIV treatment and adherence, modes of transmission and the referral pathways in Timor-Leste to support providers.
Access to medication is limited	Ministry of Health and the National AIDS Commission should conduct a national audit of the supply system and how it is regulated in light of reports of stock outs and expired medications.
At-risk groups and females are more likely to experience physical discrimination	Ministry of Health, Ministry of Social Solidarity and Inclusion and the Secretary of State for Equality and Inclusion should come together to provide HIV-specific training to LGBTI and women's groups in Timor-Leste and strengthen their networks. Ministry of Justice, The Ombudsman for Human Rights and Justice, State Secretary for Inclusion and Equality, together with other government bodies should support the setup a sex workers organization to protect the needs and rights of sex workers in Timor-Leste.

PLWH feel ashamed and fear accessing family planning services	Ministry of Health should ensure healthcare personnel are trained, competent and held accountable for providing non-judgemental family planning counselling and services. Health care personnel should provide comprehensive counselling and allow for the patient to choose their family planning method without judgement.
Client initiated HIV Voluntary Testing and Counselling is low in Timor-Leste	Ministry of Health, Ministry of Social Solidarity and Inclusion, Secretary of State for Equality and Inclusion and the National AIDS Commission should continue to investigate the existing barriers to HIV testing and promote evidence-based HIV knowledge in Timor-Leste.

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Annex 1

LAW No.4/2012 of 21 February: Labour code

SECTION III WORKERS WITH DISABILITIES OR CHRONIC ILLNESS

Article 71 General Principles

The worker or job applicant who has a disability or chronic illness shall be entitled to the rights enshrined in this Code, and shall not be discriminated against in access to employment, vocational training, career development, or working conditions. and their employment contract shall not be terminated on any of these grounds.

Article 72 Medical tests

1. The employer shall not be entitled to request that a job applicant or worker carry out medical tests, including testing for HIV, except when such tests are essential for the protection and safety of the worker, and are carried out with his/her written consent.
2. In connection with number 1 above, the employer shall not use any direct or indirect pressure on the job applicant or worker to gain their written consent to undergo medical tests.
3. All conduct by the employer that is intended to directly or indirectly pressure a job applicant or worker to agree to undergo medical tests shall be considered null and void.
4. The doctor responsible for conducting medical examinations shall inform the employer whether the worker is apt to perform the activity.
5. The employer shall make certain that the results of any examinations are kept strictly confidential.

Article 73 Confidentiality

The worker or job applicant are guaranteed the right to confidentiality surrounding information concerning their condition of health.

Article 74 Safety precautions in the workplace

The employer shall ensure that workers are not exposed to health risks, namely, contamination risks in the workplace, and shall promote awareness-raising programmes and if necessary, provide suitable equipment to protect the safety of workers.

Article 75 Suitability of the type of work and working hours

The job and working hours shall be appropriate and adjusted to suit the state of health of the worker with a disability or chronic illness.

Annex 2

Attendance list during the presentation of the preliminary results of the *HIV Stigma Index Report Timor-Leste*

LISTA PARTICIPANTES APRESENTASAUN PESKIZA RELATORIO PREVIZORIO INDISE ESTIGMA HIV BA INSTITUTO NASIONAL SAUDE (INS)

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Annex 3

Group photo after the presentation of the preliminary results of the *HIV Stigma Index Report Timor-Leste*

INS – 24 August 2018



