

**An intervention program to combat internalized stigma among people living with  
HIV/AIDS in Chennai city of Tamil Nadu, India**

Master of Public Health Integrated Experience Project

Program Implementation Framework

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## List of abbreviations

A	Agree
AIDS	Acquired immune deficiency syndrome
ANOVA	Analysis of variance
ART	Antiretroviral therapy
AUA	American University of Armenia
CEO	Chief-executive officer
D	Disagree
FSW	Female sex-workers
GHTM	Government Hospital of Thoracic Medicine
GNP	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
HSS	HIV Stigma Scale
ICRW	International Center for Research on Women
ICW	International Community of Women Living with HIV
IEC	Information, Educational and Communication
IPPF	International Planned Parenthood Federation
IRB	Institutional Review Board
MPH	Masters of Public health
MSM	Men who have sex with men
NACO	National Aids Control Organization
NACP	National AIDS Control Program
PLHIV	People living with HIV
PUD	People using drugs
SA	Strongly agree
SD	Strongly disagree
SHG	Self-help group
SPH	School of Public Health
SRC	Stigma reduction centers
STD	Sexually Transmitted Diseases
TG	Transgender people

TNSACS	Tamil Nadu State AIDS Control Society
TOT	Training of trainers
UNAIDS	United Nations Program on HIV/AIDS
WHO	World Health organization

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## **Executive summary**

**Background:** Stigma is a mark of disgrace or reproach and a perceived negative attribute, which leads one to undervalue and demean oneself. HIV/AIDS is highly stigmatized and is attributable to the fact that its routes of transmission are associated with already-marginalized behaviors (drug abuse, commercial sex work, multiple sex partners, homosexual and transgender sexual practices). HIV/AIDS stigmatization has two major components: externalized stigma and internalized stigma. Social inequality, prejudicial approach, discrimination and abuse by the society towards People Living with HIV (PLHIV) are known as externalized stigma. Externalized stigma can result in internalization of negative responses of the society in people living with HIV (PLHIV), which in turn can affect their mental wellbeing leading to low pride/self-worth/self-esteem/self-blame, isolation from society, depression, and suicide contemplation. This is commonly known as internalized stigmatization. Consequences of such internalized stigma include poor mental health of PLHIV, unsafe sexual practices, compromised life style and livelihood, rejection of HIV testing, prevention, treatment, and available support services.

**Magnitude:** In Chennai, Tamil Nadu, the magnitude of internalized stigma among PLHIV remains high. Self-blame (56%), very low self-esteem (56%), shame (53%), guilt (53%), self-punishment (24%), and suicidal-intent (26%) were predominant forms of internalized stigma observed in this population. Studies also show that actual/externalized stigma experienced by PLHIV is much less (26%) when compared to internalizing stigma (97%) in Chennai, Tamil Nadu.

**Intervention program:** The proposal suggests piloting a three-phase intervention program (socio-psychological support, information, educational and communication campaign and participatory approaches) aimed at reduction of the internalized stigma's burden and its

impact among PLHIV in Chennai city of Tamil Nadu state of India. The proposed three phase intervention will be implemented after collection of baseline data.

As a first phase of intervention, the target population will be recruited to the socio-psychological support center where a trained psychologist will assess the psychological needs of participants and render mental health first aid during the first six months of the intervention program.

In the second phase of the intervention, the participants will be assigned into several self-help groups. Information, education and communication sessions will be rendered once per month for one year. Revised version of the “Understanding and Challenging Stigma: A Toolkit for Action” will be used to train the study participants to combat internalized stigma.

The third phase of the intervention will empower the study participants by training and encouraging active participation in implementing stigma-reduction efforts to other PLHIV in their community.

**Methods:** This pilot intervention program will be evaluated to assess its effectiveness in reducing internalized stigma among target population. Target population will include PLHIV aged 18 years and above, living in Chennai city of Tamil Nadu. Simple random sampling will be used to choose participants from the intervention (Chennai) and control groups (Karur) for evaluation.

The evaluation will apply a quasi-experimental non-equivalent control group (pre and post-panel design) to estimate and compare the mean cumulative score of “internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards PLHIV” between the intervention and control groups.



**Data collection and Analysis plan:** Berger's HIV Stigma Scale (HSS), a 40-item validated and reliable scale will be used to collect baseline and follow-up data among all the participants from the intervention and the control groups.

SPSS, version 22 will be used to analyze the data. Descriptive analysis, independent t-test for comparing the means of two groups and paired t-test for comparing the baseline and follow-up means of the intervention group will be performed. ANOVA will also be conducted to analyze 'mean internalized stigma score, mean disclosure concerns score, mean negative self-image score, and mean concern with public attitudes score' between intervention and control groups respectively. Bivariate and multivariate linear regression analysis will be performed to analyze relationship between dependent and independent variables.

**Aim:** The three phase intervention program will be considered effective if we observe 30% or more reduction in the mean cumulative score of 'internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards study participants living with HIV/AIDS' in Chennai, when compared with their control group.

**Conclusion:** If the evaluation demonstrates that the three-phase intervention program is effective in plummeting internalized stigma and its impact among the study participants, then this program can be considered for a statewide implementation.

# 1. Situational analysis

## 1.1 HIV/AIDS stigmatization

According to the Webster's New World Dictionary, "stigma is a mark of disgrace or reproach that sets a person apart."<sup>1</sup> It is a perceived negative attribute, which leads one to undervalue and demean oneself. This occurs because of intense feeling of disapproval, discrimination, and condemnation from the society about attributes such as infirmity, deformity, race, religion, and nationality.<sup>2</sup>

High stigma around HIV/AIDS is partly attributable to routes of HIV transmission, which happen to be associated with already-marginalized behaviors (like drug abuse, commercial sex work, multiple sex partners, homosexual and transgender sexual practices) by the society.<sup>3,4</sup> HIV/AIDS stigmatization has two major components: externalized stigma and internalized stigma.<sup>4,5</sup> Social inequality, prejudicial approach, discrimination and abuse by the society towards People Living with HIV (PLHIV) are known as externalized stigma. Verbal stigma (taunts, gossips, rumors, blames), institutional stigma (loss of job or educational opportunities, denial of health care/ other services due to HIV status), community and household level stigma (denial of housing), and governmental stigma (discriminatory laws/policies, restriction on entry/travel/stay) are the few forms of externalized stigma.

Externalized stigma can result in internalization of negative responses of the society in PLHIV, which in turn can affect their mental wellbeing and result in low pride/self-worth/self-esteem/ self-blame, isolation from society, depression, and suicide contemplation. This is commonly known as internalized (self, enacted, felt) stigmatization.<sup>4,5</sup> According to Morrison et al. the elements of internalized stigma are internalization of context, self-perception, and protective action.<sup>6</sup> PLHIV are likely to internalize stigma and discrimination, accept deprecation, lose control and suffer from self-perception of shame, guilt, and fear. As

a response reaction, PLHIV protect themselves by avoidance, isolation and/or subterfuge.<sup>6</sup>

Facing stigmatizations poses a significant burden among PLHIV.<sup>7</sup>

Figure 1 provides a schematic format of elements of internalized stigma.<sup>6</sup> The conceptual model states that ‘precursors such as perception of societal attitude towards PLHIV and knowledge of self as HIV positive leads to perceived stigma of having HIV.’<sup>8</sup> This perception of stigma enhances as PLHIV face social disqualification, limited opportunities and negative change in social identity. This leads to responses such as avoidance, withdrawal, tension, change in self-concept, emotional reaction towards those who stigmatize, with redefined world views and priorities’. Figure 2 offers a schematic representation of the conceptual framework.<sup>8</sup> This proposal deals with HIV/AIDS-related stigma (H/A stigma) which refers to negative beliefs, thoughts, and approaches towards PLHIV, their families, and their peers.<sup>3</sup>

## **1.2 Background and significance**

### **1.2.1 Magnitude of H/A stigmatization**

It is quite difficult to measure the global burden and range of H/A stigmatization among PLHIV.<sup>7</sup> Several initiatives have identified H/A stigmatization as a major public health concern.<sup>7,9</sup> The United Nations Political Declaration on HIV/AIDS states that H/A stigmatization can be measured by tracking the discriminatory attitude among PLHIV.<sup>10</sup> The 2015 edition of the UNAIDS report estimated that in 35% of the countries with available data, more than half of the population reported discriminatory attitude towards PLHIV.<sup>10</sup> In 2016, 72 countries had HIV-specific laws and policies that litigated PLHIV for a wide-range of offences.<sup>11</sup> According to UNAIDS report, in 2013, 60% of the studied countries had laws, regulations or policies that hindered the endowment of efficient HIV prevention, and treatment and management services.<sup>12</sup>

According to the 2015 edition of the UNAIDS report, 35 countries had legislations that restrict the entry, visit, and permanent residence for PLHIV.<sup>13</sup> Of the 36.7 million PLHIV, only 60% were conscious of their HIV status; and only 53% of them aware of their HIV status had access to anti-retroviral therapy.<sup>14</sup> Another study found that on average one in every eight PLHIV is being shorn of health services.<sup>10</sup> A study conducted in Thailand found that a quarter of PLHIV in the study avoided health care services in fear of ill-treatment or disclosure without consent; 33.3% of the study participants experienced disclosure of their HIV status without their consent.<sup>15</sup> In a global study conducted among more than 2,000 PLHIV, 17% failed to reveal their HIV status to their spouse and 35% of participants were afraid of losing their family and friends due to disclosure of their HIV status.<sup>16</sup> More than a quarter (27%) of the study participants reported experiencing depression.<sup>16</sup>

### **1.2.2 Causes of stigma around HIV/AIDS**

Research conducted among overall population globally has revealed three key instantaneous actionable drivers of H/A stigma:<sup>17-19</sup>

- Absence of awareness on stigma and its damaging properties.
- Irrational fear and insufficient knowledge of HIV infection and transmission.
- Social judgment, prejudice and stereotypes against PLHIV where their values are linked with improper or immoral behavior.<sup>17-19</sup>

H/A stigma mostly revolve around several false beliefs.<sup>20</sup> A substantial proportion of people misleadingly have confidence that HIV/AIDS is always associated with death. PLHIV are labeled with personal immorality and irresponsibility, and it is believed that they deserve to be punished. Many cultural and religious institutions promote beliefs that portray PLHIV as offensive law-breakers.<sup>20</sup>

### **1.2.3 Consequences of H/A stigmatization on PLHIV**

The International Centre for Research on Women is a non-profit organization that aims to “empower women, advance gender equality and fight poverty.”<sup>21</sup> It conducts evidence based empirical research globally, and has reported that the rampant of fear, stigma/ discrimination has destabilized because of H/A stigmatization, affecting the mental health of PLHIV significantly. High levels of stress, depression, and adjustment difficulties are among stigma related problems commonly encountered by PLHIV.<sup>21</sup> Additionally, H/A stigma thwarts access to HIV testing, prevention, treatment, and support services, paving way for higher transmission,<sup>22-24</sup> and contributing to global epidemic of HIV. Stigma hampers healthy lifestyle adaptation and medical treatment adherence.<sup>24</sup> Safer sexual practices, including use of condoms, are compromised because of fear of rejection and exposure of HIV status to one’s partner.<sup>25</sup> Other potential consequences of H/A stigma include “loss of incomes and livelihood, reduced care within the health care centers, withdrawal of care in their home, loss of marriage, loss of child bearing options, loss of optimism/ confidence and feeling of insignificance, loss of reputation, public policies threatening their human rights.”<sup>19</sup> Invisibility of such serious consequences around H/A stigmatization contributes to the refutation of the problem and sets low priorities towards its reduction efforts.

### **1.3 Situation in India**

The first case of HIV was recognized at Chennai city of Tamil Nadu, India in the year 1986.<sup>26</sup> India with an HIV prevalence of 0.26% (2.1 million PLHIV)<sup>27</sup> among adults is home to the third largest HIV epidemic in the world. According to the 2015 annual report of the National Aids Control Organization (NACO), ‘Manipur has the highest HIV prevalence (1.15%), followed by Mizoram (0.80%), Nagaland (0.78%), Telangana (0.66%), Karnataka (0.45%), Gujarat (0.42%) and Goa (0.40%). In addition to these states, Maharashtra, Chandigarh,

Tripura and Tamil Nadu also have estimated adult HIV prevalence that exceed the national prevalence of 0.26% .<sup>28</sup>

In India, the most significantly affected populations, otherwise known as the high risk groups, are men who have sex with men (MSM), transgender people (TG), people using drugs(PUD), female sex-workers (FSW), migrant workers, and truck drivers.<sup>28-30</sup> The estimated prevalence of HIV among FSW, MSM, TG, PUD, migrant workers, and truck drivers are 2.2%, 4.3%, 7.5%, 9.9%, 1.0%, and 2.6% respectively.<sup>28,30</sup>

Despite the methodological challenges in quantifying H/A stigmatization, several studies conducted in India measured the discriminatory attitude among PLHIV and assessed the existing H/A stigmatization.<sup>10</sup> Aggleton et al. in a study of H/A stigma in India reported that, demonstration of higher prevalence of stigma and discrimination is observed with restraining and intimidating policies which further led to harassment of PLHIV.<sup>31</sup> Along with lack of knowledge and understanding, native ethnic beliefs add on to the opinions of “sexual wrongdoing” and fortify stigmatization and fear in India, resulting in isolation and segregation of infected population.<sup>31</sup> Sivaram et al. found strong associations between H/A stigma and avoiding HIV testing, prevention, and treatment.<sup>32</sup> In a study conducted at healthcare settings in Mumbai and Bangalore, high levels of stigma prevailed; 80% of healthcare workers showed readiness to prohibit woman PLHIV from having children, 99% supported endorsement of obligatory HIV/AIDS testing for FSW, and 83% specified that persons who attained HIV over sex or drugs “got what they deserved.”<sup>33</sup> Other studies conducted in Indian hospitals show that stigma and discrimination are revealed not only by using gloves throughout every interaction, irrespective of physical interaction, but also by notifying family members of patients about their HIV status without attaining consent,

burning the bedding of PLHIV after discharge, extra-charging PLHIV in-patients for the infection control supplies, and providing inferior health care services.<sup>34,35</sup>

### **1.3.1 Situation in Tamil Nadu, India**

Tamil Nadu, with an HIV prevalence greater than the national prevalence (i.e. 142,000 among 79 million living in Tamil Nadu are PLHIV)<sup>28,36</sup> has made efforts in quantifying stigma and discrimination in India using PLHIV Stigma Index. “PLHIV stigma index is a joint initiative of Global Network of People Living with HIV (GNP), International Community of Women Living with HIV (ICW), International Planned Parenthood Federation (IPPF), and Joint United Nations Program on HIV/AIDS (UNAIDS)”.<sup>37</sup> The index was the first of its kind to enumerate the stigma and discrimination faced by PLHIV in Tamil Nadu, and measure the forms and extent of stigma experienced by them.<sup>38</sup> PLHIV stigma index is a rich tool for collecting data on experience of self-stigma, exclusions, diagnosis experiences, disclosure decisions, disclosure experiences, discriminative health care settings, rights and laws, and effecting change.<sup>39</sup>

In the study conducted at Tamil Nadu using PLHIV Stigma index, more than half of the sample (MSM, FSW, TG and PUD) experienced at least one form of externalized stigma.<sup>37</sup> Forms of this social stigma included subjection to psychological pressure or manipulation, not being permitted to partake in religious and family happenings, verbal and physical assault, sexual rejection, and discrimination. Fifty-two percent of males, 31% of transgender individuals and 48% of females reported physical assault from their partners, in-laws and family members. Seventy-five percent of males, 74% of females, and 68% of transgender individuals reported experiencing social exclusion because of their HIV status. In spite of the strict law enforcement, studies show that 16% of PLHIV were urged to alter their residence, 11% lost their occupation, 6% were declined employment opportunity and 6% were shorn of

health care services at least once in the preceding year. The majority of the participants identified their HIV status as the reason for experiencing such externalized stigma. Lack of trust on the medical establishments and maintenance of confidentiality of medical records were among factors contributing to externalized stigma. Only 16% of the respondents were aware of the national policies and only a very few were aware of what to do when facing acts of discrimination. PLHIV were forced to perform obligatory HIV testing at job or travel associated policies (20%), they were also forced to disclose HIV status to attain residence, nationality or entry into another country (2%) and were denied insurance (2%). High levels of internalized were reported among all the participants, especially among PUD (98%), MSM (97%) and FSW (94%). Self-blame (56%), very low self-esteem (56%), shame (53%), guilt (53%), self-punishment (24%), and suicidal-intent (26%) were predominant forms of internalized stigma among PLHIV in Tamil Nadu, India. As a result of internalized stigma, respondents avoided social gathering and isolated themselves (39%), avoided marriage (29%), chose to not have any more children (37%), felt that they don't deserve sexual intimacy (19%), stopped working (14%), stopped going to hospital or local clinics even in case of emergency (13%), withdrew themselves from educational institution (10%), and avoided to apply for job promotion (10%). All the respondents reported fear of gossip and verbal insult.<sup>37</sup>

## **2. Strategy appraisal**

In 1992, the National Aids Control Organization and the Ministry of Health and Family Welfare of India launched the National AIDS Control Program (NACP: I). The program is currently at phase IV<sup>9</sup> and it aims to achieve zero infection, zero death, and zero stigma through its five main components. One of these components aims to provide 'comprehensive care, support and treatment' and as a part of providing support NACP phase IV intends to



look for opportunities to create partnership between public and private sectors and augment actions to reduce stigma/ discrimination on every level, predominantly at health care settings.<sup>9</sup>

However, availability of rich data in Tamil Nadu reveals that internalized stigma undermines the ongoing efforts for increasing the coverage of effective interventions among high-risk groups. It also hampers PLHIV from accessing any services provided by governmental or non-governmental organizations.<sup>31,32,37,40</sup> HIV testing, prevention, treatment, HIV-related health-seeking behavior, safe sexual practices, and adherence to antiretroviral therapy (ART) are outright denied by the majority of the PLHIV who perceive fear and are face internalize stigma; thus making it quite challenging to address the HIV epidemic in India.<sup>31,32,37,40</sup> In Tamil Nadu, the internalized stigma and its impacts are more prevalent and vicious than those of externalized stigma.<sup>41</sup> A study conducted by Thompson et al. in Chennai has emphasized that actual/externalized stigma experienced by PLHIV is much less (26%) as compared to internalized stigma (97%). This study also revealed that internalized stigma had an exceedingly significant adverse relationship with quality of life in environmental and psychological domain.<sup>41</sup> The findings highlight the importance of addressing the root cause, in this case, internalized stigma, and designing a program with cultural relevance to mitigate internalized stigma faced among PLHIV in Tamil Nadu, India. Addressing the root causes can help with paving way to ‘zero stigma, zero infection and zero death’.

Hence this proposal presents an intervention program for mitigating internalized stigma perceived by PLHIV initially at Chennai city of Tamil Nadu, India. Chennai city is being prioritized as the first intervention zone because of the following reasons:

- In 1986, first case of HIV was identified in Chennai city of Tamil Nadu, India<sup>26</sup> and as of 2014, prevalence of AIDS in Chennai is 15.5%, which is much higher when

compared with other regions of Tamil Nadu (Karur is the second highest with the prevalence rate of 11.96% and Salem as the third highest with 10.49% ).<sup>42</sup>

- Identified number of AIDS patient in Chennai as of 2014 were 14,663, which ranks the highest among all Tamil Nadu regions.<sup>42</sup>
- Rich data is available on the existence of internalized stigma experienced by PLHIV.
- Reaching PLHIV through governmental and non-governmental organizations and entities is highly feasible at Chennai.

### **3. Project's aim and objectives**

#### **3.1 Aim**

The aim of the proposed program is to reduce the burden of internalized stigma and its impact among the study participants living with HIV/AIDS in Chennai city of Tamil Nadu.

#### **3.1.1 Objective**

At the end of three years, after the implementation of the socio-psychological support, information, educational and communication (IEC) campaign and participatory approaches, there will be a 30%-lower cumulative score for the “internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards study participants living with HIV/AIDS” in Chennai when compared with the control group while adjusting for the baseline cumulative score.

### **4. Programming**

#### **4.1 Program planning**

This program aims to address the immediate actionable drivers of internalized stigma, which primarily include lack of awareness and understanding of internalized stigma and its speculative fears, attitudes, supposition, typecasting that drive shaming, blaming, and

devaluation of oneself. These factors can lead to adaptation of risky and negative health-seeking behaviors. The core element of the proposed program is to acclimatize human rights based approaches ('promotion of equality and non-discrimination, participation, inclusion, and accountability') to PLHIV.<sup>43</sup> The proposed program also will adapt the UNAIDS (2014) guidelines by planning programs at individual level, aiming to reduce internalized stigma through counseling and psychosocial support about stigma/ discrimination, cohesive care and support programs that elevates quality of life, and providing peer support and support groups.<sup>44</sup>

The adapted project and strategy will include a three-level intervention approach, namely:

- I. Socio-Psychological support
- II. Information, Education, Communication (IEC) approach
- III. Participatory approach

### **I. Socio-Psychological support**

“Social psychology is the empirical method of investigating psychological variables of how people's thoughts, feelings, and behaviors are influenced by the actual, imagined, or implied presence of others.”<sup>45</sup> According to WHO, “providing socio-psychological support can assist PLHIV in making informed decisions, coping better with illness and stigmas which in turn improves quality of lives, and reduces HIV epidemic.”<sup>46</sup> This program will adapt guidelines with cultural context and implement the following programs through trained socio-psychological caregiver:

- Offering individual psychotherapeutic work and counseling with professional psychologists during in-group sessions.

- Providing mental health first-aid<sup>47</sup> along with in-person trainings, teaching PLHIV participants to effectively respond to mental health problems and crises.
- Providing PLHIV with advocacy and resources to tackle internalized stigma.

## **II. Information, Education, Communication (IEC) approach**

WHO adapted a definition of IEC that refers to “a public health approach aiming at changing or reinforcing health-related behaviors in a target audience, concerning a specific problem and within a pre-defined period of time, through communication methods and principles.”<sup>48</sup>

This approach will be used in context of our proposal and the following interventions will be rendered:

- Providing information, education and counseling to PLHIV that in turn allows capacity building, networking, skill building and advocacy to overcome internalized stigma and recognize/ affirm their rights.
- Conducting self-help groups where participants are provided with interactive and secure spaces to gain knowledge, reflect, ask questions of a trusted and conversant facilitator, and gain skills for behavior change. They will also be encouraged to share their challenges and experience of overcoming crisis, sometimes not directly relating it to HIV/AIDS issue.
- Conducting mental health literacy campaigns<sup>47</sup> among PLHIV to elucidate influence of internalized stigma on quality of life and the role of accessing support in overcoming impacts and stigma in itself.
- Engaging mass media and other communication resources such as pamphlets, posters, radio, and local television channels that acquire assistance of celebrities, sports stars

and other influential people in modeling the need for seeking support to combat internalized stigma.

At the end of the 12 months of this program, PLHIV will be well equipped with skills to combat internalized stigma and learn coping strategies to free themselves from such stigmatizing experiences.

### **III. Participatory approach**

Based on several researches, a participatory approach will be adapted to empower PLHIV by training them to be ‘change agents’ among other vulnerable PLHIV groups and collectively act towards internalized stigma reduction.<sup>49,50,51</sup> Empowering PLHIV will be done by encouraging active participation in implementing stigma- reduction efforts.<sup>4,52,53</sup> The following are the programs designed under participatory approach.

- Training of trainers (TOT) and participatory learning workshops will be conducted among participants (PLHIV). This approach will equip them with skills to educate PLHIV about internalized stigma and its impact, using research based toolkit. Special emphasis will be given to discussions that would engage vulnerable PLHIV towards accessing support to combat internalized stigma. Once they completed the TOT, each PLHIV participants will be assigned to their duties and responsibilities based on needs.
- These trained participants along with trained consultants will operate hotline services to render consultations on Internalized stigma related issues.

After 2 months of theoretical classes followed by 6 months of practical sessions, PLHIV will know how to combat internalized stigma and apply coping strategies. They will also be equipped with skills to help PLHIV and teach them the skills they learned in the

program. Additionally, they will be trained as interviewers to collect data using the PLHIV stigma index. These trained PLHIV will be asked to extend their services during the scale-up of this three-phase intervention program in Tamil Nadu.

## **4.2 Program implementation**

### **4.2.1 Pre-implementation process.**

The pre-implementation tasks include:

- a. Determining the target population
- b. Acquiring support from local contributors

#### a. Determination of the target population

Inclusion criteria:

- PLHIV aged 18 years and above.
- PLHIV who are temporary or permanent resident of Chennai.
- PLHIV who understand and speak in Tamil (Native language of Tamil Nadu).

Exclusion criteria:

- PLHIV who suffers from cognitive impairment.
- PLHIV who are participating in any other specific stigma-reduction program.

This target population will be recruited from pre-anti-retroviral therapy registrations<sup>54</sup> available at Tamil Nadu State AIDS Control Society (TNSACS).

#### b. Acquiring support from other local contributors

Given that the intervention program is intense, new alliances and partnerships will be created to strengthen the program and expand its' reach. Assistance from several local organizations

that are experts in the field of community services will be acquired. At present, several governmental and non-governmental organizations in Chennai are rigorous in providing outreach services to different vulnerable groups including PLHIV. This program aims to establish an effective tie-up with TNSACS's Antiretroviral Therapy (ART) centers at Chennai including four Government Medical Institution with functioning Sexually Transmitted Diseases (STD) Department in Chennai<sup>54</sup> and six other ART facilities.<sup>55</sup> These institutions are Rajiv Gandhi Government General Hospital, Park town; Government Stanley Hospital, Royapuram; Government Royapettah Hospital, Royapettah; Government Hospital of Thoracic Medicine, Tambaram; Kilpauk medical college, Poonamalle; Institute of Obstetrics and Gynecology, Egmore and Institute of Child Health and Govt. Hospital for Children, Egmore.<sup>55</sup> This program also aims to collaborate with several non-governmental HIV/AIDS control and care center zone-wise at Chennai.

#### **4.2.2 Implementation process**

Implementation process will contain in-campus intervention and outreach intervention. As mentioned earlier, in-campus intervention will be based on a 'three-phase intervention' which was designed under the guidance of WHO and UNAIDS.<sup>43,44</sup> Main components of outreach intervention will be mental health literacy campaigns and awareness raising programs.

#### **In-campus interventions**

On their first visit to a stigma reduction center, all the recruited target population will be introduced with the informed consent and will be sent to a trained psychologist, where socio-psychological support and counseling will be provided. During the first visit, the baseline assessment of internalized stigma using PLHIV stigma index will be obtained. All the PLHIV providing consent will be included in the program. At the first phase of the intervention, the psychologists and hotline services will provide complete socio-psychological support to all

study participants. The socio-psychological support center will assess the psychological needs and offer mental health first aid. A 24-hour live answer hotline service will be available to all participants.

In the second phase of the intervention, the participants will be assigned into several self-help groups, based on their age category and gender. A medical social worker will lead each group. During sessions, a secure environment will be created to encourage PLHIV participants to learn, reflect, ask questions, and gain skills for behavior change. Self-help groups will meet once every month for a total of 12-month period. The training sessions during this 12-month period are designed to provide a friendly environment and help with building trust between study participants and the project team members; Participants who underwent educational sessions and who are willing to take part in participatory approach will be redirected to third phase of the intervention. Each participant actively attending the training sessions during the second phase of intervention will receive monthly incentives (nutrient rich food provision).

In the third phase of the intervention, the participants will be trained to lead workshops, empathize and offer counseling, conduct mental health literacy campaigns among PLHIV and recruit them to be beneficiaries of the program. This program will be designed to have both theoretical and practical experience. The training will last for 2 months and they will work on field for 6 months. Participants who take-part in participatory approach will receive salary on monthly basis.

### **Resources for educational sessions**

Information, Education and TOT will be based on adapted and revised version of “Understanding and Challenging Stigma: A Toolkit for Action”<sup>56</sup> which was published by International Center for Research on Women (ICRW), International HIV/AIDS Alliance and



other renowned organization and was funded by UNAID. This toolkit is a learner-centered, participatory training that aims to facilitate discussion on HIV-related stigma, promote a change in attitude and practice, and develop strategies to confront stigma. This toolkit has eight modules (A-H) to train the trainers and more specifically modules D-H will be used to address internalized stigma and coping up strategies directly among PLHIV. These specific modules (D-H) will be adapted in the educational sessions that includes discussion, presentation, smaller group discussion, report backs, rational brainstorming, pictures, role-plays or drama, warm-up games, and songs.

These sessions will equip the study participants with tools to:

- Combat internalized stigma and the shame that's associated with it
- Reconstruct their self-esteem.
- Enhance suitable skills towards anti-stigma action
- Develop practical coping-up strategies for challenging stigma and discrimination.
- Deal with the HIV diagnosis.

Undergoing Module A-H will help medical social workers, community leaders, field workers and TOT to:

- Acknowledge the existence of stigma and its impact on PLHIV.
- Understand the necessity to change ones' attitudes and actions, which reduces stigma.
- Improve the profundity and eminence of understanding about HIV/AIDS to combat fears and misconceptions.
- Care, encourage PLHIV, and encourage in a loving, non-stigmatizing way.
- Conduct effective educational sessions in their SHG using the toolkit provided.

- Conduct mental health literacy campaigns, awareness programs and hot-line services.

### **Outreach interventions**

Mental health literacy campaigns and awareness programs will be conducted in PLHIV community at TNSACS affiliated institutions in Chennai, to illuminate the impact of internalized stigma on mental health along with quality of life and the role of accessing support in overcoming internalized stigma. Brochures, pamphlets, posters and mass media will be utilized to advertise and create awareness on internalized stigma and benefits of participating in the proposed program in short time interval. Home visits by medical social workers and SHG will be done when feasible, with provision of support, counseling and encouragement.

#### **4.2.3 Locations to implement SRC**

The proposed program will establish three stigma reduction centers (SRC) near Government Hospital of Thoracic Medicine (GHTM) in Tambaram, Rajiv Gandhi Government General Hospital in Park town and Government Kilpauk Medical College & Hospital in Kilpauk. The rationale for choosing these locations is to have higher feasibility and easy accessibility to the target population. It is also important to note that Government Hospital of Thoracic Medicine at Chennai is the largest AIDS care center in the country. It renders services to 300 in-patients and 300 outpatients each day. This hospital exclusively serves PLHIV and Tuberculosis patients.

#### **4.2.4 Allocation of human, financial and other resources**

Chief executive officer, who will be an HIV specialist with a Masters of Public health (MPH) degree and at least three years of experience, will direct the proposed program. Chief-executive officer (CEO) of the program will supervise and direct the functioning of the

administrative officer, accounts officer, and program managers. Administrative officer will provide administrative aid in human resources, communication and information management systems, at the SRC. Accounts officer with a junior accountant will co-ordinate with CEO and manage financial resources of the program. They will also ensure efficient and effective functioning of the financial operations. CEO will control and delegate funding to the program on need basis. A Program manager will lead each SRC. The program manager has the prime responsibility of initiating, planning, designing, executing, monitoring, controlling, and completing the program. Three program managers will take the leadership responsibility of their respective SRC and will manage and synchronize program activities, information and technology services, and resources such as human resources, financial resources, and material resources. Each SRC will have 2 operational teams. The first team will consist of two psychologists, a psychiatrist, a physician and a nurse per SRC, while the second team will consist of trained social workers and field workers. These teams will function under the project managers' supervision and will be key players in the project implementation.

The key personnel involved in this project will be trained in various capacities to attain:

1. In-depth knowledge on Internalized stigma and its impacts and ways to combat it.
2. Good inter-personal and intra-personal communication skills.
3. Capacity to plan and organize educational sessions.
4. Skills to promote awareness and endorse real-world activities to challenge internalized stigma.
5. Capacity to train audience with the skills that they acquired.

CEO will fund the SRC and provide material resources on a monthly basis. These monthly funds include salary, rent, electricity charges, travel expenses and maintenance charges such

as the internet, telephone and replenishment of office supplies; and the material resources includes educational materials, toolkit for training, medical and pharmacological supplies and office utilities. Figure 3 presents the proposed Project Team.

#### **4.2.5 Timeline**

The proposed program will start on January 1, 2019 and end on December 31, 2021. The first six months will be spent on planning the following:

- Hiring and recruiting the required human resources.
- Identifying and renting the premises for SRC offices at Chennai.
- Establishing effective referral systems.
- Identifying and recruiting program participants.

The three phases of intervention will follow the planning phase. The evaluation will be conducted in September and October 2021 to assess the research questions among the study participants. The final report will be prepared in November and December 2021. Appendix 1 provides further details about the timeline.

#### **4.3 Program evaluation**

This section focuses on designing strategic actions to quantitatively measure and evaluate the impact of the proposed three-phase intervention program on the study participants by evaluating the project's objectives.

This section presents the proposed evaluation plan under the following subheadings:

- Evaluation questions and hypothesis
- Study design
- Study population

- Sampling strategy
- Sample size
- Study variables
- Study instruments
- Data management and analysis
- Ethical considerations
- Reporting the results

#### **4.3.1 Methods and materials**

##### **4.3.1.1 Evaluation question and hypothesis**

###### **Primary research question**

After implementing three-phase intervention of socio-psychological support, IEC, and participatory approach, will there be a 30%-lower mean cumulative score of ‘internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes, towards study participants living with HIV/AIDS’ in Chennai relative to the control group after adjusting for the baseline cumulative score?

###### **Secondary research questions**

- Is there a reduction in mean internalized stigma score in the intervention group compared to the control?
- Is there a reduction in mean disclosure concerns score in the intervention group compared to the control?

- Is there a reduction in mean negative self-image score in the intervention group compared to the control?
- Is there a reduction in mean concern with public attitudes score in the intervention group compared to the control?

## **Hypothesis**

Null Hypothesis: The reduction difference between the PLHIV participants and control group on mean cumulative score of ‘internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards PLHIV’, after the implementation of three- phase intervention program will be less than 30%.

Alternative hypothesis: There will be 30% or more reduction mean cumulative score of ‘internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards study participants living with HIV/AIDS’ in Chennai, when compared with their control group, by three years.

### **4.3.1.2 Evaluation design**

For the evaluation purpose, quasi-experimental non-equivalent control group (pre and post-panel design) will be used.<sup>57</sup>

The control group will provide information on the changes that are not associated with the intervention, thus increasing the internal validity of the evaluation study. To avoid contamination, the control group participants will be selected from Karur district of Tamil Nadu. Karur ranks the second highest in the geographical distribution of AIDS cases (Male: 7.86%; Female: 4.10%) after Chennai with 15.51% (Male: 10.34%; Female:5.16%) as of 2014.<sup>42</sup> In the same year, 11,310 PLHIV were registered in Karur that is again the second highest when compared with 14,663 PLHIV in Chennai. Other similarities between Chennai

and Karur such as cultural background, native language, geographical and climatic conditions, administration and politics, law and order, and economy justify selection of the control group subjects from Karur.<sup>42</sup> After collecting the data for evaluation, the control group subjects will receive an incentive of one-time nutrition rich food provision, travel allowance and booklet providing coping strategies for combating internalized stigma. The evaluation study will employ a panel design (same individuals in both baseline and the follow-up). The quasi-experimental design will help to identify wide-ranging trends from the results, especially in disciplines of social science (in our case, psychological aspects of internalized stigma) and increase feasibility because it has little or no association with time and logistical constraints.<sup>57,58</sup> However, certain limitations of this design do exist. For instance, due to lack of randomization, internal validity is at threat and conclusions regarding causality are less definitive.

Table1. Design of the evaluation study – Campbell & Stanley nomenclature:

Group	Pre-test	Treatment	Post-test
Intervention group = E	O1	X	O2
Control Group =C	O1		O2

Where,

O1 denotes pretest at intervention and control groups.

O2 denotes posttest at intervention and control groups.

X is the structured intervention program.

#### **4.3.1.3 Evaluation population.**

The evaluation population includes:

Intervention group:

PLHIV, aged 18 years or above, with ability to understand and speak in Tamil, living temporarily or permanently in Chennai.

Control group:

PLHIV, aged 18 years or above, with ability to understand and speak in Tamil, living temporarily or permanently in Karur.

#### 4.3.1.4 Sampling strategy

The proposed evaluation will use simple random sampling method for the intervention and control group.<sup>59</sup> In simple random sampling, each study participant has equal probability to be included in the sample. This method will minimize the potential of selection bias within each group (intervention and control) and will increase likelihood of obtaining a representative sample for each group.<sup>59</sup> The evaluation team will obtain the enrollment list of study participants who registered themselves in the three-phase intervention program. This enrollment list will serve as the sampling frame for the intervention group. TNSACS HIV patients' registry will be requested and will be used as sampling frame for the control group. Sampling unit will be person living with HIV. All random selection will be done using "Rand-between" command of Microsoft Office Excel software.

Table 2: Overview of sampling strategy:

	Intervention group	Control group
Sampling design	Simple random sampling	Simple random sampling
Sampling frame	Enrollment list	TNSACS registry
Sampling unit	Individuals	Individuals



#### **4.3.1.6 Study variables**

The main independent variable of interest is the presence or absence of the three-phase intervention program.

#### **Dependent variables**

The primary dependent variable is the cumulative mean score providing an overall summary for the internalized stigma subscales ('disclosure concerns subscale, negative self-image subscale, and concern with public attitudes towards PLHIV subscale').

The secondary dependent variables include the mean score from each individual subscales

Sub-scales' mean scores

- mean internalized stigma score,
- mean disclosure concerns score,
- mean negative self-image score, and
- mean concern with public attitudes score.

While primary dependent variable determines the correlation between the intervention program and outcome of interests cumulatively, sub-scales such as mean internalized stigma score, mean disclosure concerns score, mean negative self-image score, and mean score of concern with public attitudes will be individually calculated. This will be done so to determine if one sub-scale is more responsible than the other in affecting the outcome variable of interest.

## Covariates

The covariates include age, gender, marital status, educational level, employment status, socio-economic status and the presence of co morbidities(see appendix 2 for the study variables).<sup>8</sup>

### 4.3.1.7 Sample size calculation

The sample size is calculated based on the continuous outcome variable with difference in sample means of two groups. In a study conducted by Li et al, HIV/AIDS patients living in diasporic communities of Canada (African/ Caribbean, Asian and Latino communities), underwent an intervention to combat internalized stigma in the year 2017.<sup>60</sup> The difference in sample means of the intervention and control groups and standard deviation of their study is being adapted to calculate the sample size of this study.

$$\text{Formula}^{61} \quad : \quad N = \frac{2(Z_{\alpha} + Z_{\beta})^2(1 + (n-1)p)}{n[(\mu_1 - \mu_2) / \sigma]^2}$$

Where,

$$Z_{\alpha} \quad : \quad 1.645$$

$$Z_{\beta} \quad : \quad 0.84$$

$$p \quad : \quad 0.9 \text{ (90\%)}$$

$$n \quad : \quad 2 \text{ (pre and post assessment)}$$

$$\sigma \quad : \quad 6.5$$

$$\Delta = \mu_1 - \mu_2 \quad : \quad 2.61$$

Sample size for one group N= 74

By adjusting for 30% lost to follow up, sample size was calculated to be 97 for one group; thus making our total sample size to be 194.

#### **4.3.1.8 Study instruments**

HIV Stigma Scale (HSS) is a 40-item validated and a reliable instrument that was developed based on psychosocial aspects of being infected with HIV and on the extensive literature review regarding stigma.<sup>8</sup> It primarily measures the stigma perceived by PLHIV by addressing all the aspects of the conceptual model (see figure 2).

The proposed study will include the HSS in its questionnaire. The first section of the questionnaire will include questions on socio-demographic characteristics, and the second section will contain the HSS collecting data on perceived stigma under four domains of ‘internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV’ (see appendix 3 for the questionnaire). The guidelines for the total HSS scores can range from 40 to 160 (1 score to 4 score for each of the 40 items, i.e.  $1 \times 40 = 40$  to  $4 \times 40 = 160$ ). The internalized stigma scores, disclosure scores, negative self-image scores and concern with public attitudes scores range between 18 to 72, 10 to 40, 13 to 52, and 20 to 80, respectively. The range of liable scores depends on the number of question items in the scale and their response options. The questionnaire will be translated into and administered in Tamil (native language). A 4-point Likert-type scale (strongly disagrees, disagree, agree, and strongly agree) will be used to respond to HSS items<sup>8</sup>. The questionnaire will be piloted before its use.

#### **4.3.1.9 Data collection**

All eligible PLHIV will be invited to the intervention program. The baseline data (pre-test assessment) collection will be conducted among both intervention and control groups during July 2019. Participants will be randomly chosen from the enrollment list of intervention

group from Chennai and from TNSACS HIV patients' registry of control group from Karur. This record consists of registered PLHIV cases. After the collection of baseline data, the three-phase intervention program among the intervention group. Then the post-test assessment will be done among intervention and control group on September 2023. Field workers and medical social workers will serve as interviewers and they will be adequately trained by the professionals in the SRC offices and journal forms will be given to them for data collection (See Appendix 5). The instruments and interviewers will not differ from the baseline assessment.

#### **4.3.1.10 Threats to internal validity with quasi-experimental design**

**History:** Occurrence of various other events related to our outcome of interest may occur during the 3 years of planned intervention time. This might bias the outcome variable of interest. This threat is inevitable; however, assuming the control group is also exposed to such events, the comparison between the intervention and control groups will be less susceptible to this threat.

**Testing:** Using the same questionnaire in pre-test and post-test may influence the participants' response. Though this threat is inevitable, it can be minimized by having a control group study.

**Attrition:** Attrition might be a major threat to the internal validity of this study. However, loss to follow-up has been considered. Depending on the levels of attrition and its mechanism within the groups, it can be a potential threat to internal validity. The study team will compare the characteristics of those who drop out of the study with those who stay in the study to understand if attrition is a big threat.

Instrumentation: Given that the same instrument will be used in this study during pre-test and post-test to the intervention and control groups, the instrumentation is not a threat to internal validity of this study.

Compensatory rivalry: Since the participants will be blinded to the existence of a control group, compensatory rivalry is not a threat to internal validity.

Maturation: People mature naturally with time. Given that our study follows a panel design, we include same people at base-line and follow-up. Since the evaluation will continue for three consecutive years' maturation could be a threat to internal validity. This threat can also be minimized by comparing the results of the intervention and the control groups.

Selection: This could be a threat to internal validity since the intervention and control groups are from different cities, and the difference between the groups could be due to different characteristics of participants and not the intervention of interest.

#### **4.3.1.11 Threats to external validity**

Hawthorne effect or Reactive/Situational effects: This can be a threat to the control group as well as to the intervention group. Knowing that their performance is being evaluated through pre and post questionnaires might influence the way the participants answer the knowledge and behavior related questions. Hence, implementing similar intervention in a different setting without the evaluation might not lead to similar results.

Testing/intervention interaction: The change in cumulative mean score of internalized stigma can occur because of pretest and intervention and not just the intervention program.

Interaction between the intervention program and the baseline measurement can potentially threaten the external validity of this study if the intervention is implemented in other settings without the baseline measurement.

Selection intervention interaction: This is a threat to external validity because the results might not be generalizable to PLHIV in different settings.

Multiple intervention interferences: Different ongoing programs may occur in different regions, in addition to the proposed intervention; hence the effect of the intervention might not be the same if implemented in other settings affecting the external validity of this study.

#### **4.3.1.12 Data management and analysis**

After collecting the data, the program manager will forward the questionnaires to be entered by the data entry personnel. Data cleaning will then be done by checking the outliers, missing values, and distribution of variables using exploratory analysis. SPSS, version 22 will be used to analyze all the data. Descriptive analysis, independent t-test for comparing the means of two groups and paired t-test for comparing the baseline and follow-up means of intervention group will be performed. ANOVA will also be conducted to analyze 'mean internalized stigma score, mean disclosure concerns score, mean negative self-image score, and mean concern with public attitudes score' between intervention and control group respectively. Bivariate and multivariate linear regression analysis will be performed to analyze relationship between dependent and independent variables.

#### **4.3.1.13 Ethical considerations**

Oral informed consent will be obtained from every study participant before intervention and pre-test. Keen attention will be paid on maintaining confidentiality (including personal details and collected data) of each participant. The risks and benefits of their participation will be well-informed. Every effort will be taken to cause no harm to the participants. The protocol of the proposed program was reviewed and approved by the Institutional Review Board (IRB) of the American University of Armenia (AUA) (see appendix 6 for consent form)

#### **4.3.1.14 Reporting the results**

After completing the evaluation process, the final report will be produced and under the authorization of the chief executive officer, the final report will be delivered to the donor organization.

#### **4.3.2 Evaluation team**

Trained field workers will approach the participants and collect their data which will be submitted to their respective SRC program manager. Program manager will hold prime responsibility in collecting questionnaire from the field workers, forwarding the questionnaire to the data entry staff and performing evaluation process under co-ordination and supervision of CEO. Program manager will solely be responsible for quality check and assurance of confidentiality as well. The chief evaluator, who will lead the entire evaluation process, will be hired to avoid conflict of interest. Under the authorization of CEO, the final evaluation report will be reviewed and submitted to donor organization.

### **5. Budgeting**

The proposed program seeks 711, 960 USD for operational expenses and 159,140USD for administrative expenses. The direct in-campus intervention would cost around 483,000USD.

It is also important to consider that in-campus intervention budget also includes the salaries of PLHIV who takes part in the participatory approach (third-phase of intervention).

Outreach intervention will approximately need US\$567,000. Hence the total budget for the program will be approximately 1, 921,100 USD (see appendix 7 for budget of the program).

All the monetary values for the budgeting were based on market value of Chennai metropolitan city.

## 6. Summary

The proposed program uses an evidence based approach and has designed a three-phase intervention program based on the recommendations of WHO and UNAIDS, to reduce the burden of internalized stigma among PLHIV in Chennai. This 3-phase intervention includes: Socio-Psychological support (6 months), IEC approach (12 months) and Participatory approach (8 months). The training for IEC and participatory approach will be based on adapted and revised version of the “Understanding and Challenging Stigma: A Toolkit for Action.” Consequently, the program aims not only to reduce internalized-stigma and endow coping up strategies among PLHIV, but it also aims to equip them to be “change agents” among vulnerable PLHIV population. Incentives in the form of nutrition rich food provision will be given to PLHIV participants. Public health professionals, physicians, nurses, medical social workers and field workers are the key players of the program. PLHIV Stigma index will be used as the primary assessment tool. The impact of the program will be evaluated and the final report will be delivered to the donor organization. We are expecting a significant reduction in internalized stigma and its impact among PLHIV at Chennai and we are expecting to produce well-equipped “change agents” for the scale-up project. If the evaluation demonstrates that the three-phase intervention program is effective in plummeting internalized stigma and its impact among study participants, then this program can be commended for a statewide implementation.



## References

1. Agnes M. *Webster's New World Dictionary - Google Books*. 4th ed. Simon and Schuster
2. Salters-Pedneault Kristalyn. Verywell|What is Stigma and How Does it Apply to Mental Health? <https://www.verywell.com/stigma-a-definition-of-stigma-425329>. Published 2017. Accessed August 5, 2017.
3. UNAIDS|Reduction of HIV-related stigma and discrimination. 2014. <http://www.unaids.org/en/ourwork/programmebranch/>. Accessed August 5, 2017.
4. Aggleton, P., Wood, K., Malcolm, A., & Parker R. UNAIDS|HIV -Related Stigma, Discrimination and Human Rights Violations:Case studies of successful programmes. 2005. [http://data.unaids.org/publications/irc-pub06/jc999-humrightsviol\\_en.pdf](http://data.unaids.org/publications/irc-pub06/jc999-humrightsviol_en.pdf). Accessed August 5, 2017.
5. Castro A, Farmer P. Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. *Am J Public Health*. 2005;95(1):53-59. doi:10.2105/AJPH.2003.028563
6. Morrison K. *USAID|Stigma, Discrimination, Internal Stigma, and HIV.*; 2006. [http://www.policyproject.com/pubs/generalreport/Breaking\\_the\\_Cycle.pdf](http://www.policyproject.com/pubs/generalreport/Breaking_the_Cycle.pdf). Accessed August 7, 2017.
7. *WHO | Progress Report 2011: Global HIV/AIDS Response*. World Health Organization; 2015. [http://www.who.int/hiv/pub/progress\\_report2011/en/](http://www.who.int/hiv/pub/progress_report2011/en/). Accessed August 5, 2017.
8. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Res Nurs Health*. 2001;24(6):518-529. doi:10.1002/nur.10011
9. NACP-IV Components | National AIDS Control Organization | MoHFW | GoI. <http://naco.gov.in/nacp-iv-components>. Accessed April 21, 2017.
10. *UNAIDS | On the Fast-Track to End AIDS by 2030- Focus on Location and Population.*; 2015. [http://www.unaids.org/sites/default/files/media\\_asset/WAD2015\\_report\\_en\\_part01.pdf](http://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf). Accessed August 7, 2017.
11. Bernard EJ, Cameron S. *Building Momentum in Global Advocacy against HIV Criminalisation*. England: HIV Justice Network; 2016. [http://www.hivjustice.net/wp-content/uploads/2016/05/AHJ2.final2\\_.10May2016.pdf](http://www.hivjustice.net/wp-content/uploads/2016/05/AHJ2.final2_.10May2016.pdf). Accessed August 14, 2017.
12. UNAIDS. *UNAIDS Report on the Global AIDS Epidemic 2013.*; 2013. [http://www.unaids.org/sites/default/files/media\\_asset/UNAIDS\\_Global\\_Report\\_2013\\_en\\_1.pdf](http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Global_Report_2013_en_1.pdf). Accessed August 7, 2017.
13. UNAIDS. Lithuania confirms no restrictions on entry, stay and residence for people

- living with HIV | UNAIDS. UNAIDS.  
[http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2015/september/20150917\\_Lithuania](http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2015/september/20150917_Lithuania). Published 2015. Accessed August 14, 2017.
14. UNAIDS. *UNAIDS Fact Sheet - Latest Statistics on the Status of the AIDS Epidemic.*; 2017.  
[http://www.unaids.org/sites/default/files/media\\_asset/UNAIDS\\_FactSheet\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf). Accessed August 7, 2017.
  15. Li MJ, Murray JK, Suwanteerangkul J, Wiwatanadate P. Stigma, social support, and treatment adherence among HIV-positive patients in Chiang Mai, Thailand. *AIDS Educ Prev*. 2014;26(5):471-483.  
<http://guilfordjournals.com/doi/pdf/10.1521/aeap.2014.26.5.471>. Accessed August 7, 2017.
  16. Nachega JB, Morroni C, Zuniga JM, et al. HIV-Related Stigma, Isolation, Discrimination, and Serostatus Disclosure. *J Int Assoc Physicians AIDS Care*. 2012;11(3):172-178. doi:10.1177/1545109712436723
  17. Khuat Thi Hai O, Ashburn K, Pulerwitz J, Ogden J, Nyblade L. Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination. 2008. <http://www.popline.org/node/210633>. Accessed August 7, 2017.
  18. Nyblade L, Pande R, Mathur S, et al. ICRW |Disentangling HIV and AIDS Stigma in Ethiopia,Tanzania and Zambia. 2003. <http://ihi.eprints.org/415/>. Accessed August 7, 2017.
  19. Ogden J, Nyblade L. Common at its core: HIV-related stigma across contexts. 2005. <http://www.popline.org/node/262087>. Accessed August 7, 2017.
  20. Mo `awad E, Ebied E-S. Factors Contributing To HIV/AIDS – Related Stigma and Discrimination Attitude in Egypt: Suggested Stigma Reduction Guide for Nurses in Family Health Centers. *J Educ Pract* . 2014;5(24). [http://pakacademicsearch.com/pdf-files/edu/413/35-46 Vol 5, No 24 \(2014\).pdf](http://pakacademicsearch.com/pdf-files/edu/413/35-46%20Vol%205,%20No%2024%20(2014).pdf). Accessed August 7, 2017.
  21. Major B, O'Brien LT. The Social Psychology of Stigma. *Annu Rev Psychol*. 2005;56(1):393-421. doi:10.1146/annurev.psych.56.091103.070137
  22. *Health and Human Rights Resource Guide*. 5th ed. FXB Center for Health and Human Rights and Open Society Foundations.; 2013. <https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf>. Accessed August 7, 2017.
  23. Zierler S, Cunningham WE, Andersen R, et al. Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *Am J Public Health*. 2000;90(2):208-215. <http://www.ncbi.nlm.nih.gov/pubmed/10667181>. Accessed August 7, 2017.
  24. Chesney MA, Smith AW. Critical Delays in HIV Testing and Care. *Am Behav Sci*. 1999;42(7):1162-1174. doi:10.1177/00027649921954822
  25. Preston DB, D'Augelli AR, Kassab CD, Cain RE, Schulze FW, Starks MT. The

- Influence of Stigma on the Sexual Risk Behavior of Rural Men Who Have Sex with Men. *AIDS Educ Prev.* 2004;16(4):291-303. doi:10.1521/aeap.16.4.291.40401
26. Simoes EA, Babu PG, John TJ, et al. Evidence for HTLV-III infection in prostitutes in Tamil Nadu (India). *Indian J Med Res.* 1987;85:335-338. <http://www.ncbi.nlm.nih.gov/pubmed/3623641>. Accessed August 7, 2017.
  27. *UNAIDS Prevention Gap Report.*; 2016. [http://www.unaids.org/sites/default/files/media\\_asset/2016-prevention-gap-report\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf). Accessed August 7, 2017.
  28. *National AIDS Control Organization: Annual Report 2015.*; 2015. [http://naco.gov.in/sites/default/files/Annual Report 2015-16\\_NACO.pdf](http://naco.gov.in/sites/default/files/Annual%20Report%202015-16_NACO.pdf). Accessed August 7, 2017.
  29. *Narrative Country Progress Report of India: Global AIDS Response Progress Reporting 2015.*; 2015. doi:GOI/NACO/SIM/GR-RPT/200415
  30. *NACO | HIV Data 2015.*; 2015. [http://www.naco.gov.in/sites/default/files/HIV DATA.pdf](http://www.naco.gov.in/sites/default/files/HIV%20DATA.pdf). Accessed August 7, 2017.
  31. Aggleton P. HIV and AIDS-related stigmatization discrimination and denial: forms contexts and determinants. Research studies from Uganda and India. 2000. <http://www.popline.org/node/175350>. Accessed August 7, 2017.
  32. Sivaram S, Zelaya C, Srikrishnan AK, et al. Associations Between Social Capital and HIV Stigma in Chennai, India: Considerations for Prevention Intervention Design. *AIDS Educ Prev.* 2009;21(3):233-250. doi:10.1521/aeap.2009.21.3.233
  33. Ekstrand ML, Ramakrishna J, Bharat S, Heylen E. Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *J Int AIDS Soc.* 2013;16(3 Suppl 2):18717. doi:10.7448/ias.16.3.18717
  34. Surlis S, Hyde A. HIV-Positive Patients' Experiences of Stigma During Hospitalization. *J Assoc Nurses AIDS Care.* 2001;12(6):68-77. doi:10.1016/S1055-3290(06)60185-4
  35. Ginsburg AS, Hoblitzelle CW, Sripipatana TL, et al. Health workers' views on quality of prevention of mother-to-child transmission and postnatal care for HIV-infected women and their children. *AIDS.* 2007;21(18):2529-2532. doi:10.1097/QAD.0b013e3282f155f4
  36. Population of Tamil Nadu 2017- Tamil Nadu Population- Current Population in Tamilnadu. <http://www.indiaonlinepages.com/population/tamil-nadu-population.html>. Accessed August 7, 2017.
  37. *The People Living with HIV Stigma Index: A Report from Tamilnadu, India.*; 2011. [http://www.aidsdatahub.org/sites/default/files/documents/Tamil\\_Nadu\\_Stigma\\_Index\\_report.pdf](http://www.aidsdatahub.org/sites/default/files/documents/Tamil_Nadu_Stigma_Index_report.pdf). Accessed August 7, 2017.
  38. GNP, ICW, IPPF, UNAIDS. The people living with HIV stigma index: Building the

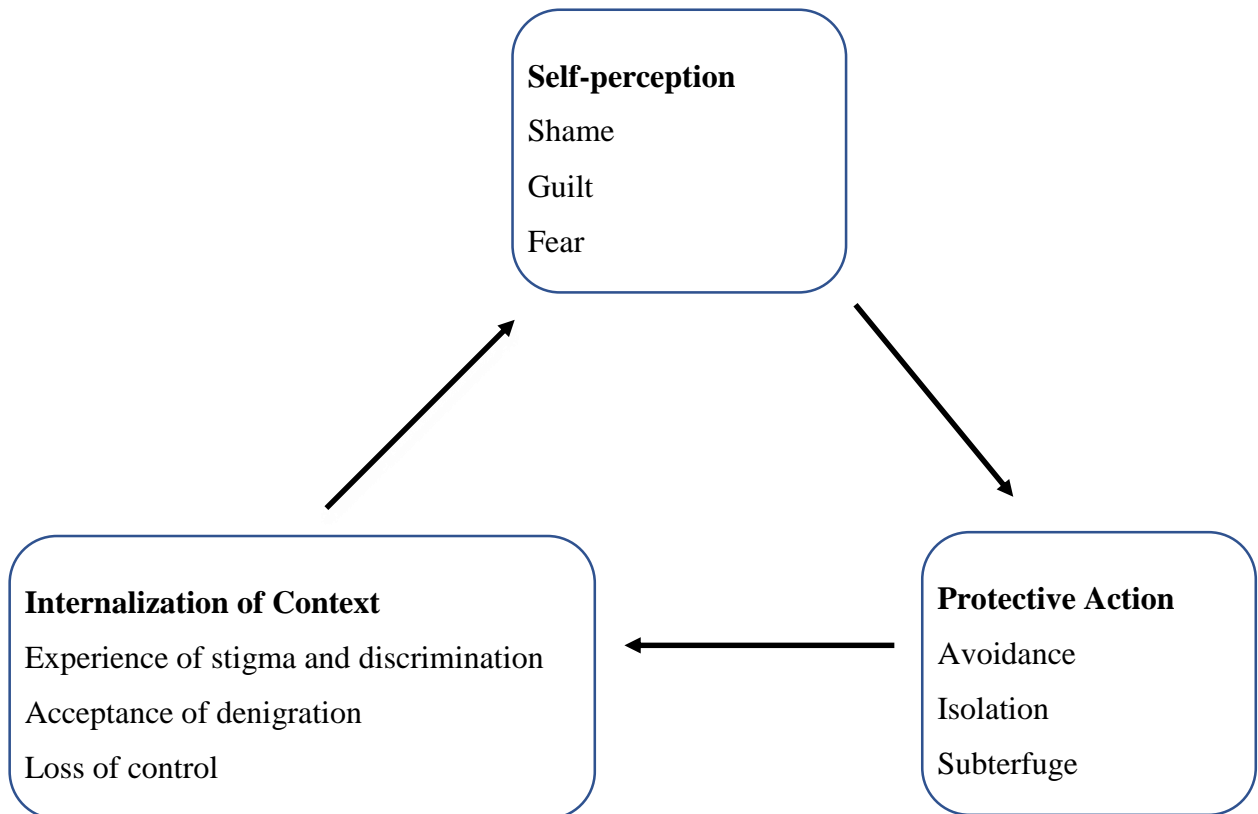
- evidence base for understanding the stigma and discrimination experienced by people living with HIV in different countries. 2008:1-76.  
[http://www.stigmaindex.org/sites/default/files/page-attachments/UserGuide\\_FINAL\\_complete0055.pdf](http://www.stigmaindex.org/sites/default/files/page-attachments/UserGuide_FINAL_complete0055.pdf). Accessed September 18, 2017.
39. Sharp L, Paterson H. *PLHIV Stigma Index: Questionnaire, Pointers and Qualitative Exploration*. United Kingdom  
<http://www.stigmaindex.org/sites/default/files/reports/HappyHealthyHot1-PLHIV Stigma Index Questionnaire.pdf>. Accessed September 26, 2017.
  40. Mahajan AP, Sayles JN, Patel VA, et al. Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*. 2008;22(Suppl 2):S57-S65. doi:10.1097/01.aids.0000327438.13291.62
  41. Thomas BE, Rehman F, Suryanarayanan D, et al. How stigmatizing is Stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India. *AIDS Care*. 2005;17(7):795-801. doi:10.1080/09540120500099936
  42. Kalyani V, Vasanthi R. A Geographical Distribution of Aids Cases in Tamilnadu District Wise (2008 – 2014). *J Eng Res Appl*. 2015;5(25):2248-962290.
  43. UN Economic and Social Council. General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant). *UN Comm Econ Soc Cult Rights*. 2000;2000(14):2,7,19. doi:E/C.12/2000/4
  44. *UNAIDS |Global AIDS Response Progress Reporting-Construction of Core Indicators for Monitoring the 2011 United Nations Political Declaration on HIV and AIDS;* 2014.  
[http://www.unaids.org/sites/default/files/media\\_asset/GARPR\\_2014\\_guidelines\\_en\\_0.pdf](http://www.unaids.org/sites/default/files/media_asset/GARPR_2014_guidelines_en_0.pdf). Accessed August 7, 2017.
  45. Fiske ST, Gilbert DT, Lindzey G. Handbook of social psychology. 2010:118.  
[http://web.mit.edu/curhan/www/docs/Articles/15341\\_Readings/Motivation/Pittman\\_1998\\_Motivation.pdf](http://web.mit.edu/curhan/www/docs/Articles/15341_Readings/Motivation/Pittman_1998_Motivation.pdf). Accessed August 7, 2017.
  46. WHO | Psychosocial Support. WHO.  
<http://www.who.int/hiv/topics/psychosocial/support/en/>. Published 2006. Accessed August 7, 2017.
  47. Betty Kitchener AM, Jorm T. What We Do at Mental Health First Aid | Mental Health First Aid. <https://mhfa.com.au/about/our-activities/what-we-do-mental-health-first-aid>. Published 2000. Accessed August 7, 2017.
  48. Clift E. Information, education and communication : lessons from the past; perspectives for the future. 2001:1-42.  
[http://apps.who.int/iris/bitstream/10665/67127/1/WHO\\_RHR\\_01.22.pdf](http://apps.who.int/iris/bitstream/10665/67127/1/WHO_RHR_01.22.pdf). Accessed August 8, 2017.
  49. Heijnders M, Van Der Meij S. The fight against stigma: An overview of stigma-reduction strategies and interventions. *Psychol Health Med*. 2006;11(3):353-363.

doi:10.1080/13548500600595327

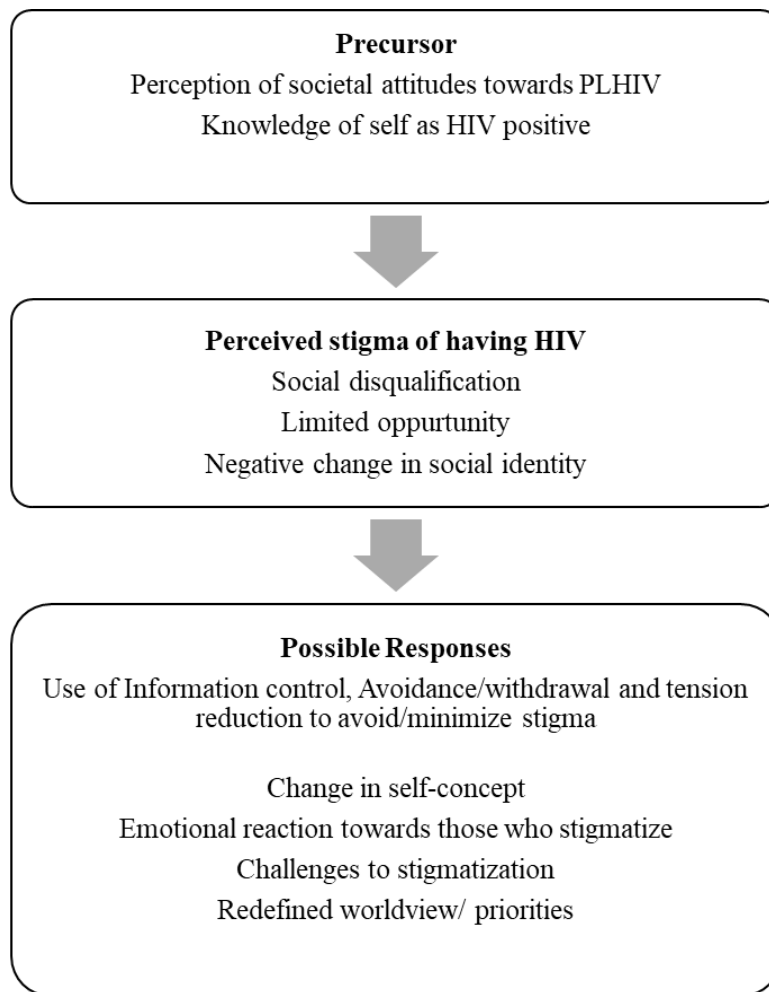
50. UNAIDS. *Reducing HIV Stigma and Discrimination: A Critical Part of National AIDS Programmes*. UNAIDS; 2007. <http://www.unaids.org>. Accessed August 8, 2017.
51. Campbell C, Foulis CA, Maimane S, Sibiyi Z. "I have an evil child at my house": Stigma and HIV/AIDS management in a South African community. *Am J Public Health*. 2005;95(5):808-815. doi:10.2105/AJPH.2003.037499
52. Huurne D. HIV and AIDS related stigma and discrimination; Current thinking and lessons learnt. *Intern Doc*. 2006.
53. Nyblade L, Thu K, Nguyen H, et al. Communities Confront HIV Stigma in Viet Nam Participatory Interventions Reduce HIV-Related Stigma in Two Provinces. 2008:1-41. <https://www.icrw.org/wp-content/uploads/2016/10/Communities-Confront-HIV-Stigma-in-Vietnam.pdf>. Accessed August 8, 2017.
54. Tamil Nadu State AIDS Control Society. Health and Family Welfare Department. Government of Tamil Nadu. <http://www.tnhealth.org/tshiv.htm>. Accessed August 8, 2017.
55. List of ART Facilities | Tamil Nadu State Aids Control Society. <http://tnsacs.in/list-of-art-facilities/>. Accessed August 8, 2017.
56. Center for Research on Women I. *Understanding and Challenging HIV Stigma: Toolkit for Action - Cambodia Edition*. <http://www.hivpolicy.org/Library/HPP001877.pdf>. Accessed May 3, 2017.
57. Weiner J. Research Design for HSRE: Part 1. The Johns Hopkins University. [http://ocw.jhsph.edu/courses/HSRE/PDFs/HSRE\\_lect4\\_weiner.pdf](http://ocw.jhsph.edu/courses/HSRE/PDFs/HSRE_lect4_weiner.pdf). Published 2007. Accessed August 8, 2017.
58. Campbell D, Stanley J. Experimental and Quasi experimental designs for Research. In: *Experimental and Quasi Experimental Designs for Research*. ; :1-38. [http://www.uky.edu/~clhyn2/PS671/CS\\_part1.pdf](http://www.uky.edu/~clhyn2/PS671/CS_part1.pdf). Accessed August 8, 2017.
59. Gravetter FJ, Forzano L-AB. *Research Methods for the Behavioral Sciences, Stamford: Cengage Learning. Hare CE, McLeod J (1997). Developing a Records Management Programme.*; 2011.
60. Li AT-W, Fung KP-L, Maticka-Tyndale E, Wong JP-H. Effects Of HIV stigma reduction interventions in diasporic communities: insights from the CHAMP study. *AIDS Care*. October 2017:1-7. doi:10.1080/09540121.2017.1391982
61. Hedeker DR, Gibbons RD. *Longitudinal Data Analysis*. Wiley-Interscience; 2006.

## Figures

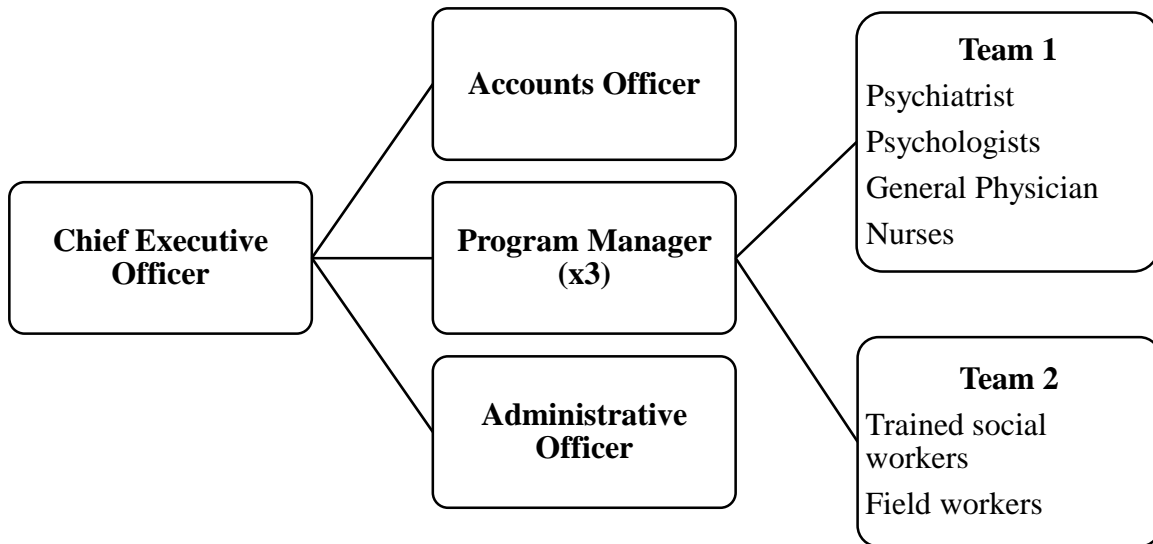
**Figure 1: Elements of internalized stigma<sup>6</sup>**



**Figure 2: Conceptual model**



**Figure 3: The project team**





## Appendixes

### Appendix 1: Timeline chart for the proposed program

	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
2019	Planning Phase						Phase I: Socio-psychological support					
2020	Intervention Phase: II: Information, Education and communication approach											
2021	Intervention Phase: III: Participatory approach								Evaluation		Final Report	

## Appendix 2: Study variables

<b>Independent variables:</b>	
Presence or absence of the three phase intervention-program	Dichotomous
<b>Dependent variables:</b>	
<b>Primary:</b> Cumulative score of internalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards PLHIV	Continuous
<b>Secondary:</b> Internalized stigma score Disclosure concerns score Negative self-image score Public attitudes score	Continuous
<b>Covariates:</b>	
Age	Continuous
Gender	Categorical
Marital status	Categorical
Educational level	Ordinal
Place of residence	Categorical
Employment status	Categorical
Socio-economic status	Ordinal
Monthly spending of the family	Ordinal
Years of being diagnosed with HIV/AIDS	Continuous
Co-infections	Categorical
Chronic conditions	Categorical

## Appendix 3: Questionnaire

### Socio-demographic data

Read the questions carefully and check the appropriate box.

**1. Date of birth (day/month/year) \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_**

#### **2. Gender**

- 1. Male
- 2. Female

**3. Place of residence \_\_\_\_\_**

#### **4. Education**

- 1. Incomplete Secondary Education
- 2. Secondary School
- 3. Technical Education
- 4. Graduate/Postgraduate Education
- 99. I refuse to answer

#### **5. Family status**

- 1. Single
- 2. Married
- 3. Divorced
- 4. Widowed
- 99. I refuse to answer

#### **6. How would you rate your social status?**

- 1. Substantially below average
- 2. Little below average

- 3. Average
- 4. Little above average
- 5. Substantially above average
- 99. Not sure/difficult to response

**7. In an average how much money does your family spend monthly?**

- 1. Less than 5 000 rupees
- 2. 6 000 – 10 000 rupees
- 3. 11 000 – 20 000 rupees
- 4. 21 000 – 30 000 rupees
- 5. More than 30 000 rupees
- 99. I don't know/ I refuse to answer

**8. Are you employed?**

- 1. Yes
- 2. No
- 99. I refuse to answer

**9. When were you diagnosed with HIV? month / year \_\_\_\_\_**

**10. Do you have any one of these co-infections?**

- 1. Hepatitis C
- 2. Hepatitis B
- 3. Tuberculosis
- 4. Other (Specify) \_\_\_\_\_
- 5. No co-infections

**11. Please, indicate any chronic health problem(s) that you presently have. (Mention all that apply)**

- 1. High blood pressure
- 2. Heart disease

- 3. Lung disease (including asthma)
- 4. Stomach/intestine disease
- 5. Cancer
- 6. Kidney problem
- 7. Problems with joints/bones
- 8. Other problems (describe) \_\_\_\_\_
- 9. No chronic health problems

**Berger HIV stigma scale** ©1999

This study asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the letters or numbers that go with your answer. There are no rights or wrong answers. Feel free to write in comments as you go through the questions. This first set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question. For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), or strongly agree (SA).

NO.	Question items	SD	D	A	SA
1.	In many areas of my life, no one knows that I have HIV				
2.	I feel guilty because I have HIV				
3.	People's attitudes about HIV make me feel worse about myself				
4.	Telling someone I have HIV is risky				
5.	People with HIV lose their jobs when their employers find out				
6.	I work hard to keep my HIV a secret				

7.	I feel I am not as good a person as others because I have HIV				
8.	I never feel ashamed of having HIV				
9.	People with HIV are treated like outcasts				
10.	Most people believe that a person who has HIV is dirty				

11.	It is easier to avoid new friendships than worry about telling someone that I have HIV				
12.	Having HIV makes me feel unclean				
13.	Since learning I have HIV, I feel set apart and isolated from the rest of the world				
14.	Most people think that a person with HIV is disgusting				
15.	Having HIV makes me feel that I'm a bad person				
16.	Most people with HIV are rejected when others find out				
17.	I am very careful who I tell that I have HIV				
18.	Some people who know I have HIV have grown more distant				
19.	Since learning I have HIV, I worry about people discriminating against me				
20.	Most people are uncomfortable around someone with HIV				

21.	I never feel the need to hide the fact that I have HIV				
22.	I worry that people may judge me when they learn I have HIV				
23.	Having HIV in my body is disgusting to me				

Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

No.	Question item	SD	D	SA	A
24.	I have been hurt by how people reacted to learning I have HIV				
25.	I worry that people who know I have HIV will tell others				
26.	I regret having told some people that I have HIV				

27.	As a rule, telling others that I have HIV has been a mistake				
28.	Some people avoid touching me once they know I have HIV				
29.	People I care about stopped calling after learning I have HIV				

30.	People have told me that getting HIV is what I deserve for how I lived my life				
31.	Some people close to me are afraid others will reject them if it becomes known that I have HIV				
32.	People don't want me around their children once they know I have HIV				
33.	People have physically backed away from me when they learn I have HIV				
34.	Some people act as though it's my fault I have HIV				
35.	I have stopped socializing with some people because of their reactions to my having HIV				
36.	I have lost friends by telling them I have HIV				
37.	I have told people close to me to keep the fact that I have HIV a secret				
38.	People who know I have HIV tend to ignore my good points				
39.	People seem afraid of me once they learn I have HIV				
40.	When people learn you have HIV, they look for flaws in your character				



#### **Appendix 4: Guidelines for scoring the Berger HIV stigma scale and subscales**

Items are scored as follows:

Strongly disagree = 1; disagree = 2; agree = 3; strongly agree = 4.

‘If a subject selects a response in between two options (e.g.: between SD and D), a numerical value midway between the two options would be used (e.g.: 1.5). Two items are reverse-scored: items 8 and 21. After reversing these two items, each scale or subscale’s score is calculated by simply adding up the raw values of the items belonging to that scale or subscale. Subscale designations appear in small print in the far right margin of the instrument; it may be desirable to cover or delete those numbers before reproducing the instrument for administration to subjects. Sixteen items belong to more than one subscale, reflecting the inter-correlations of the factors on which the subscales are based. The range of possible scores depends on the number of items in the scale. For the total HIV Stigma Scale, scores can range from 40 to 160 [1 x 40 items to 4 x 40 items]. For the personalized stigma subscale, scores can range from 18 to 72. For the disclosure subscale, scores can range from 10 to 40. For the negative self-image subscale, scores can range from 13 to 52. For the public attitudes subscale, scores can range from 20 to 80.’

## Appendix 5: Journal form

#	Eligible PLHIV Name	Age	Phone number	Referral Institution	Baseline		Follow-up	
					Attempt 1	Attempt 2	Attempt 1	Attempt 2
					Date/Result code	Date/Result code	Date/Result code	Date/Result code
001								
002								
003								
004								
005								
006								
007								
008								
009								
010								

### Result codes:

1. Completed survey
2. Participant was not available at home
3. Participant was unable to participate because of severe health condition
4. Participant was unable to participate because of business
5. Postponed interview
6. Refusal to participate
7. Participant is incompetent \_\_\_\_\_
8. Incomplete interview \_\_\_\_\_
9. Other \_\_\_\_\_

## **Appendix 6: Informed consent form for intervention group (English Version)**

### **American University of Armenia**

#### **Institutional Review Board**

Hello, my name is Samantha Grace. I am a second year graduate student of the Gerald and Patricia Turpanjian School of Public Health (SPH) at the American University of Armenia. With the support of the faculty members from the Gerald and Patricia Turpanjian School of Public Health of the American University of Armenia and in collaboration with Tamil Nadu AIDS Control society (TNSACS). I am conducting a program to combat internalized stigma and its impact on people living with HIV aged 18 years old and above in Chennai. You have been contacted because you have been registered under TNSACS. Your participation is voluntary and if you are willing to participate, I will ask few questions about HIV/AIDS related stigmatization that you perceive. You can attend the socio-psychological support program and educational sessions even if you do not participate in the survey. During each session, you will be offered free nutritional food provisions each month. If you are willing to participate in training that will equip you to be a change agent among your PLHIV community, you will receive salary till the end of this program (8 months). At the end of these 3 programs, you will be contacted again to complete another survey. The total duration of the interview will be 30 minutes. You can skip any question if you feel discomfort or not willing to answer and you can stop the interview at any time. The information you provide for this survey will be confidential and only the summary of information from all participants will be presented in the final report. By participating in this survey, there will not be any risk to you and the information provided by you will be very helpful for science and healthcare. If you have more doubts about the survey, you can contact the principle investigator of the study, Dr. Vahe Khachadourian at the American University of Armenia (AUA), School of

Public Health at vkhachadourian@aua.am. If you feel you have not been treated fairly or think you have been hurt by participating in this survey, please contact Ms. Varduhi Hayrumyan, the Human Subject Protection Administrator of the American University of Armenia (37460) 61 25 62. Do you agree to participate? Thank you. If yes, shall we continue?

**American University of Armenia**

**Institutional Review Board**

**Consent form for control group (English Version)**

Hello! I am Samantha Grace working for one of HIV/AIDS Stigma reduction program. The aim of this project is to reduce the burden of HIV/AIDS stigmatization among PLHIV. You have been approached as one of the participants in this survey since you are living in Karur district and you are registered under Tamil Nadu AIDS control society. Your participation is voluntary and if you are willing to participate, I will ask few questions about your perception on HIV/AIDS and stigma that revolves around it. The total duration of the interview will be 30 minutes. You can skip any question if you feel discomfort or not willing to answer and you can stop the interview at any time. You will later be contacted to complete another survey. The information you provide for this survey will be confidential and only the summary of information from all participants will be presented in the final report. By participating in this survey, there will not be any risk to you and the information provided by you will be very helpful for science and healthcare. In addition, after the second survey, you will be provided with nutritional food provision for a month and educational materials that will be helpful to improve your knowledge about dealing with HIV/AIDS stigmatization. If you have more doubts about the survey, you can contact the principle investigator of the study, Dr. Vahe Khachadourian at the American University of Armenia (AUA), School of Public Health at [vkachadourian@aua.am](mailto:vkachadourian@aua.am). If you feel you have not been treated fairly or think you have been hurt by participating in this survey, please contact Ms. Varduhi Hayrumyan, the Human Subject Protection Administrator of the American University of Armenia (37460) 61 25 62.

Do you agree to participate? Thank you. If yes, shall we continue?

## Appendix 7: Budget for the proposal

<b>Appendix 7a: Budget for Operational and administrative expenses</b>							
<b>I.</b>	<b>Operational Expenses (Personnel)</b>	<b>Type of appointment</b>	<b>Type of payment</b>	<b>No. of unit</b>	<b>Amount in USD per unit-month</b>	<b>Duration of work in months</b>	<b>Total Amount in USD</b>
	Chief executive officer	Full-time	Fixed Monthly	1	2000	36	72,000
	Project Manager	Full-time	Fixed Monthly	3	1000	36	1,08,000
	Administrative officer	Full-time	Fixed Monthly	1	750	36	27,000
	Chief Accountant	Part-time	Fixed Monthly	1	350	30	12,600
	Junior Accountant	Part-time	Fixed Monthly	1	100	30	3,600
	Chief Evaluator	Part-time	Fixed per hour	1	1000	2	2000
	Data entry personnel	Part-time	Fixed Per hour	2	200	1	400
	Psychiatrist	Full-time	Fixed-monthly	3	1100	36	118,800
	Psychologist	Full-time	Fixed-monthly	6	935	36	201,960
	Physician	Part-time	Fixed per hour	3	300	36	32,400
	Nurses	Part-time	Fixed per hour	3	150	36	16,200
	Field workers	Part-time	Fixed per hour	15	100	24	36,000
	Social workers	Part-time	Fixed per hour	9	100	36	32,400
	Maintenance staffs (Clerical assistance, janitors, watchmen)	Full-time	Fixed-monthly	9	150	36	48,600

<b>II</b>	<b>Administrative Expenses</b>	<b>Type of appointment</b>	<b>Type of payment</b>	<b>No. of unit</b>	<b>Amount in USD per unit-month</b>	<b>Amount in USD for 3 years.</b>
<b>a.</b>	<b>Space and Utilities:</b>					
	Office rent	NA	Fixed monthly	3	500	54,000
	Office electronics and equipment:					
	Windows 8 PC	NA	One-time payment	3	1000	3,000
	Printer & Scanner	NA		3	160	480
	Office Furniture set	NA		3	7800	23,400
	Office supplies (stationeries)	NA	Per month	3	50	5,400
<b>b.</b>	<b>Travel Expenses:</b>					
	Vehicles	NA	One-time payment	1	8000	8000
<b>c.</b>	<b>Communication</b>					
	Telephone	NA	One-time payment	3	20	60
	Internet Postage	NA	Fixed monthly	3	100	10,800
<b>d.</b>	<b>Other Direct costs:</b>					
	Maintenance Miscellaneous	NA	Fixed monthly	3	500	54,000



### Appendix 7b: Budget for in-campus and outreach Interventions

<b>III.</b>	<b>In-Campus Intervention</b>	<b>Type of payment</b>	<b>Amount in USD per unit-per SRC-month</b>	<b>Amount in USD for 3 SRC</b>
1.	Education materials	One-time payment	2000	6000
2.	Electronics for educational purposes	One-time payment	1500	4500
3.	Education session expenses (For PLHIV and TOT)	Fixed monthly	500	36,000
4.	Food provisions	Once per month for 12 months	150 (Estimation: 194 PLHIV per SRC)	349,200
5.	Participatory PLHIV	Fixed per hour for 8 months	150 (Estimation: 97 PLHIV per SRC)	87,300

<b>IV.</b>	<b>Outreach Intervention</b>	<b>Amount in USD for 3 years.</b>
1.	Mental health literacy campaigns	250,000
2.	Awareness programs	150,000
3.	Hotline Services	167,000
	Campaign and awareness program utilities includes brochures, pamphlets, posters, electric and electronic appliance (microphone, speakers, projectors), mass media expenses and miscellaneous expenses	

**Estimated grand total of the intervention and evaluation of the proposed program**

	<b>Areas of Expenditure</b>	<b>Total Amount in USD for 3 years</b>
1.	Operational expenses	711,960
2.	Administrative expenses	159,140
	<b>Total</b>	<b>871,100 USD</b>
3.	In-campus intervention	483,000
4.	Outreach intervention	567,000
	<b>Total</b>	<b>1,050,000 USD</b>
	<b>Grand total</b>	<b>1,921,100 USD</b>