

# A global HIV stigma reduction framework adapted and implemented in five settings in India

## SUMMARY REPORT

**For India's National AIDS Control Programme (NACP), reducing HIV stigma and discrimination is a critical component of the national response to the epidemic. Stigma reduction is included as a key element in NACP IV (2012–2017).**

To support the NACP, the International Center for Research on Women (ICRW) with the United Nations Development Programme (UNDP), has:

- adapted an existing global HIV stigma reduction framework for the Indian context
- pilot tested the framework in five settings in India
- synthesized lessons learned about the feasibility and relevance of the framework for use by the NACP and other global stakeholders in informing stigma reduction interventions and measurement.

Overall, ICRW found that the global framework was relevant to the Indian context and feasible for use by organizations and institutions in guiding stigma-reduction programme development, implementation and measurement. Learning from the pilot interventions offers guidelines for broader implementation.

## Context

Despite a 57% reduction in HIV prevalence among the general population in India over the last decade<sup>1</sup>, the epidemic persists among key populations most vulnerable to HIV infection, including men who have sex with men (MSM), sex workers and injecting drug users<sup>2</sup>. Greater efforts are needed to reduce the barriers these groups face in accessing HIV prevention, care, treatment and support services.

Among these barriers are different forms of stigma and discrimination:

- **HIV stigma**
- **stigma against marginalized and vulnerable groups**
- **intersecting stigmas**

It is now well established that stigma and discrimination fuel HIV transmission and impede access to programmes and services<sup>3</sup>. Stigmatizing attitudes in the general population and discriminatory treatment by actors ranging from health-care providers to local policy-makers intensify the marginalization of vulnerable groups at highest risk, driving them further from the reach of health services and much-needed prevention, treatment, care and support. Likewise, the anticipation and internalization of stigma among key populations impede HIV-related health-seeking behaviour and adherence to antiretroviral therapy (ART)<sup>4,5</sup>.

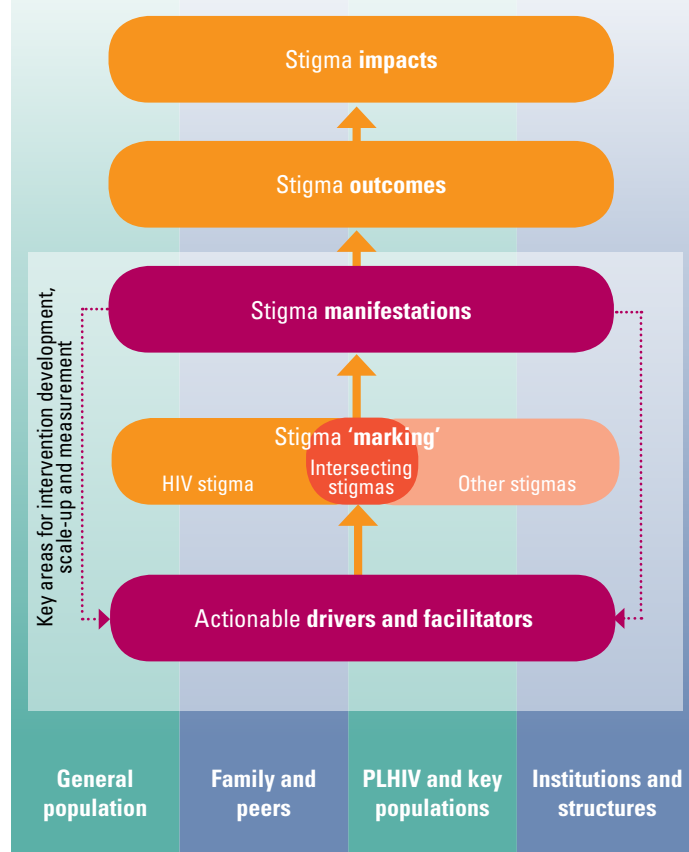
## The stigma reduction framework

The global framework adapted for the Indian context was developed by a consortium of stigma researchers<sup>6</sup> and was based on a systematic review and synthesis, supported by UNAIDS, of the research literature. The framework (see Figure 1) highlights practical entry points for stigma and discrimination reduction programming and measurement, and is intended to inform the integration of stigma reduction activities into national AIDS responses. India is the first country to pilot the global framework and assess its feasibility and appropriateness for guiding stigma-reduction efforts.

The stigmatization process occurs among the general population, family and peers, people living with HIV (PLHIV), key populations and within institutions and structures. The framework focuses on factors that drive or facilitate HIV stigma, termed 'actionable' because they can change positively as the result of an intervention. *Drivers* include:

- **lack of awareness of stigma and its harmful consequences**
- **social judgment**
- **fear of infection through casual contact**

Figure 1. Reducing HIV stigma and discrimination: A framework for programme implementation and measurement<sup>7,8</sup>



While the drivers are generally negative, *facilitators* could influence the stigmatization process either negatively or positively. For example, laws that protect the rights of people living with HIV may reduce discrimination, whereas laws that criminalize HIV can fuel stigma and discrimination. Drivers and facilitators lead to *stigma manifestations*, such as internalized stigma – the acceptance of negative beliefs and feelings about oneself – and discrimination. The manifestations go on to influence the outcomes (e.g. HIV care-seeking behaviours, ART adherence) and impacts of stigma (e.g. HIV incidence, quality of life) in a given context.

The framework assumes that any individual can anticipate, experience and/or perpetuate HIV stigma and discrimination, regardless of his or her HIV status. It acknowledges that HIV stigma often intersects with other stigmas, such as those around sexual orientation and behaviour, gender, drug use and poverty.

## Implementation and activities

In support of India's commitment to reducing HIV-related stigma and discrimination articulated in the NACP-IV, ICRW engaged five organizations working with diverse populations in three states<sup>9</sup>, to implement stigma-reduction activities over a nine-month period (Table 1) guided by the global framework. Four of the projects were structural in nature and targeted individuals within institutions, including hospitals, employers, Gram Panchayat and schools. One project sought to integrate stigma-reduction activities for female sex workers and their families within existing targeted interventions. Key findings and lessons learned across the five organizations informed specific adaptations of the framework for the Indian context and provide important insights for developing implementation guidelines for stigma-reduction programming.



## Key findings

Specific findings relevant to the various components of the framework are described below, with emphasis on adaptations to make the framework better suited to the Indian context.

### Framework feasibility and appropriateness

Overall, ICRW found that the global framework was relevant to the Indian context and feasible for use by organizations and institutions to guide stigma-reduction programme development, implementation and measurement.

→ **Fear of infection and social judgment – two key actionable drivers of stigma in the framework – are prevalent among the different populations and need to be the focus of intervention and measurement efforts.**

Despite many years of information campaigns about how HIV is transmitted, fear of becoming infected with HIV through casual contact with a PLHIV persists among the general population, key populations and

health-care workers. For example, Humsafar Trust found that about half (47 percent) of hospital para-medical staff feared touching the sweat of an HIV-positive person. High proportions were also fearful of such practices as taking blood pressure, changing bedpans and changing the clothes of an HIV-positive patient. Among the medical staff, fear was greatest when sharing utensils with an HIV-positive person and touching his/her sweat. Among female sex workers, KHPT found that two-thirds felt PLHIV should be isolated and half were not willing to share or eat food with an HIV-positive friend or family member.

Social judgment, similarly, demands attention. A survey of hospital workers by Humsafar Trust revealed that many hold attitudes of 'blame and shame' towards PLHIV and MSM. As many as two-thirds of paramedical workers thought that PLHIV should be ashamed of themselves and 28 percent thought that MSM do not deserve to receive treatment. Similarly, GSNP+ found that a third of workers surveyed felt that PLHIV should not be allowed to continue working.

→ **It is important to work with multiple target populations in interrupting the actionable drivers of stigma.**

The adapted framework highlights four key groups/environments in which stigma-reduction efforts are needed: general population, family and peers, PLHIV and key populations and institutions and structures. Consistent with previous research, the projects demonstrated the value of working with more than one group at a time in influencing stigma's drivers.


- St. Xavier's College recognized that in order to change students' attitudes towards PLHIV they needed to also work at the institutional level to get buy-in from administrators as well as train the teachers to impart the training for students.
- Humsafar Trust realized that in order to increase care-seeking behaviour among MSM they needed to work not only with MSM on internalized stigma but also with health institutions on policies and with health workers on attitudes and practices.
- Swasti found that to have an effect on community-level stigma it was necessary not only to work with community members but also to engage with the Gram Panchayat. Another critical component of Swasti's intervention was supporting PLHIV to lead stigma-reduction efforts with community and Gram Panchayat members.

→ **The framework's inclusion of 'intersecting stigmas' is critical, given the nature of the epidemic in India and its focus on targeted interventions.**

The projects that focused on key populations – female sex workers in the case of KHPT and MSM in the case of Humsafar Trust – demonstrate how HIV stigma is linked with other stigmas in response to certain behaviours or attributes. For example, quality of care for positive MSM is not likely to improve if an intervention focuses only on improving health-care workers' attitudes towards PLHIV. In fact, attitudes and practices around homosexuality must also be addressed. Likewise, to reduce stigma in the community and family directed at HIV positive sex workers, it was necessary to address negative attitudes about sex work as well as HIV infection.

→ **Application of the framework revealed the need for two additions important for the Indian context: the inclusion of family and peers as a distinct target population and the addition of 'occupation' and 'caste' as examples of intersecting stigma.**

The original framework included family and peers as part of the general population. However, KHPT recognized the importance of this group as distinct from the general population in addressing stigma directed toward female sex workers. A new column was added to the framework, highlighting the importance of family and peers. The other change made to the global framework was the addition of 'occupation' and 'caste' as examples of intersecting stigma which are particularly relevant in the Indian context.

 **Table 1.** Activities conducted to test the framework, by implementing organization

IMPLEMENTATION ORGANIZATION AND PROJECT AIM	TARGET POPULATION	SITE	MAIN ACTIVITIES
<p><b>St. Xavier's College</b> To test the framework in an educational setting</p>	<p>Institutional management team, faculty and students</p>	<p>Ahmedabad, Gujarat</p>	<ul style="list-style-type: none"> <li>• 20 faculty members were trained in stigma reduction and, in turn, trained 60 students.</li> <li>• Students met with female sex workers (FSWs), members of the gay and transgender communities and people living with HIV (PLHIV).</li> <li>• Students shared their experiences and the changes they underwent at a reflection meeting after the visits.</li> <li>• Students conducted a campaign to take the project's key messages to a larger audience.</li> <li>• Pre- and post-surveys showed reductions in stigmatizing attitudes among students.</li> </ul>
<p><b>Karnataka Health Promotion Trust (KHPT)</b> To understand and address the multiple layers of stigma faced by rural FSWs living with HIV</p>	<p>Programme staff of targeted interventions, FSWs and family members</p>	<p>Belgaum and Bagalkot districts, Karnataka</p>	<ul style="list-style-type: none"> <li>• Focus group discussions and in-depth interviews were held with FSWs living with HIV to understand their concerns.</li> <li>• FSWs participated in a three-day workshop to map where they face HIV-related stigma and to discuss its forms, causes and effects on PLHIV and their families and their knowledge about HIV and gaps in services.</li> <li>• Group sessions were held with FSWs and family members on combating social stigma.</li> <li>• FSWs who disclosed their status received counseling to address internalized stigma.</li> <li>• FSWs and others were identified and trained to be champions for improving the situation of positive sex workers.</li> <li>• The project reached a total of 1,900 FSWs and family members.</li> </ul>
<p><b>Swasti</b> To build and sustain a diverse group of volunteers to combat negative attitudes towards PLHIV through the engagement of local governance systems (Panchayats)</p>	<p>Panchayat members; members from the local health, education and law enforcement sectors; PLHIV; community members</p>	<p>Nandi Panchayat, Karnataka</p>	<ul style="list-style-type: none"> <li>• 22 Gram Panchayat members, 30 key stakeholders and 14 PLHIV were trained during the course of implementation</li> <li>• Sensitization trainings were held for Gram Panchayat members followed by trainings for health providers, teachers, Anganwadi workers, police and other local leaders.</li> <li>• Panchayat members passed a resolution condemning stigmatizing behaviour directed at PLHIV, which was painted on walls in five of the villages under the Nandi Panchayat.</li> <li>• Through mobilization by Panchayat members, sensitization campaigns were held in the villages to increase awareness.</li> <li>• Trainings were conducted with those volunteering to be 'stigma busters' in the community.</li> <li>• Swasti shared the project's findings with all involved stakeholders.</li> </ul>
<p><b>Gujarat State Network of Positive People (GSNP+)</b> To address the stigma and discrimination faced by PLHIV in workplaces by creating an enabling environment that protects their rights</p>	<p>Key leadership team from industrial houses, members of human resource and corporate social responsibility divisions and workers/laborers</p>	<p>Surat, Gujarat</p>	<ul style="list-style-type: none"> <li>• A sensitization meeting was held with industrial associations to dispel myths about HIV and gain buy-in to work with individual industries.</li> <li>• GSNP+ worked with five industries at three levels: with human resource and management to bring about policy changes; with corporate social responsibility to garner support for sustainability and replication of activities; and with the workers to assess their knowledge and attitudes for informing subsequent sensitization trainings.</li> <li>• A total of 357 workers were surveyed.</li> <li>• Sensitizations with human resource of the selected industries were conducted and GSNP+ is working with them to develop policy guidelines.</li> </ul>
<p><b>Humsafar Trust</b> To capture the level of stigma and discrimination in health settings and internalized stigma among men who have sex with men (MSM)</p>	<p>Health workers from a public and a private hospital, members of the MSM community</p>	<p>Mumbai, Maharashtra</p>	<ul style="list-style-type: none"> <li>• A total of 200 medical and para-medical staff from both hospitals were surveyed.</li> <li>• A workshop and group discussion was conducted with MSM.</li> <li>• A policy review was conducted with heads of hospital departments.</li> <li>• A consultation was conducted with hospital and NGO representatives and MSM to discuss the findings and develop action plans to address stigma and discrimination.</li> </ul>

## Framework implementation

The experiences of the five organizations confirmed that national guidance on implementing the framework should emphasize two elements: using a multi-level approach to stigma reduction and incorporating contact strategies.

### → Using a range of activities concurrently enables a multi-level approach and maximizes stigma reduction efforts.

Consistent with previous research<sup>10,11</sup>, implementing organizations found that it was critical to work at multiple levels (institutional, community, family and individual-level) and with multiple stakeholders (e.g. community opinion leaders, general public, PLHIV, health providers) to both reduce stigma and foster the enabling social environment needed to support lasting changes in attitudes and behaviours. For example, Humsafar and KHPT found that it was important to address both internalized stigma among MSM and sex workers, respectively, while also tackling stigmatizing attitudes held by health-care workers or family and peers. In order to work at multiple-levels concurrently, it is often necessary to implement a few different activities. These activities will vary by target population. Swasti, for example, held intensive stigma-reduction workshops with Gram Panchayat members to increase awareness of stigma and decrease negative attitudes, but used community sensitization campaigns for the same purpose with general community members.

### → Contact strategies are a key component for stigma reduction.

The pilot interventions confirmed existing global evidence about the importance of contact strategies. For example, St. Xavier's College found that providing students with an opportunity to visit organizations of sex workers, MSM and transgenders was integral to the stigma reduction course. These visits provided opportunities for contact with members of groups that are highly stigmatized and helped break down previously held stigmatizing attitudes and beliefs.



## National implementation: Building on pilot projects

Each of the five projects yielded tangible stigma-reduction outputs and insights that can be adapted or expanded upon by NACP to enhance stigma-reduction efforts nationally.

- **Sharing a stigma reduction curriculum for college students.** The curriculum developed by St. Xavier's College has the potential for broad use, including for students training to be doctors, nurses and social workers.
- **Integrating stigma reduction within targeted interventions.** KHPT's project demonstrated that it is possible and valuable to integrate stigma reduction activities within existing targeted interventions. KHPT's project provides a template that can be applied to other targeted interventions.
- **Engaging Gram Panchayat members directly in community stigma reduction efforts.** Swasti's project was the first in India to target and engage Gram Panchayat members specifically as both a target and implementer of stigma-reduction efforts in rural communities. This pilot programme can inform the scale-up of structural interventions at the community-level that work within existing rural institutions.
- **Engaging with workplace associations as entry points for stigma-reduction activities.** GNSP+ found that it was necessary to first engage workplace associations in stigma reduction efforts and then target individual organizations. This is an important insight for future stigma reduction efforts in workplace settings.
- **Building on data on internalized stigma among MSM and stigmatizing attitudes and practices among health care providers.** The survey research conducted by Humsafar Trust provided critical data on barriers to engagement in care for MSM and the quality of care currently being provided to MSM. These data can inform the development of multi-level interventions to reduce internalized stigma among MSM and to reduce fear of HIV infection and 'blame and shame' towards MSM and PLHIV among health-care workers.

## Endnotes

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