# Global consensus statement on HIV-related stigma

To inform targeted actions and resource allocation for HIV services and policy efforts, it is imperative to clearly articulate the burdens, types, and manifestations of HIV-related stigma. In 2022, the Heart of Stigma programme of the IAS - International AIDS Society conducted a Delphi process, guided by a multi-agency steering group, to establish consensus on critical concepts, measures, and strategies for addressing HIV-related stigma at national and global levels.

This process led to the formulation of the global consensus statement (Table 1) and call to action (Table 2) that you can find below.

For more details, visit <u>iasociety.org/ias-programme/heart-stigma</u> or email <u>nostigma@iasociety.org</u>

# Table 1: Consensus points on reducing HIV-related stigma at scale following two rounds of the Delphi process

# Theme and consensus points

- 1. The importance of addressing HIV-related stigma at scale
- 1.1 It is important to understand how stigma and discrimination are being experienced
- 1.2 It is important to measure stigma in a systematic and thorough manner in order to reach global HIV targets.
- 2. HIV-related stigma terms and definitions
- 2.1 It is important to achieve consensus on definitions and use of stigma-related language.
- 2.2 Achieving consensus on definitions would enable comparability, cross-setting learning and efforts to assess progress towards global targets.
- 3. Frameworks
- 3.1 Conceptual frameworks are useful in research, real-world intervention development, and policy on health-related stigmas.
- 3.2 Frameworks based on underlying stigmatization processes and how they manifest should be more frequently used in research, intervention development and policy on health-related stigmas.
- 4. Programming and approaches
- 4.1 It is important for all pre-service and in-service healthcare providers to be trained on HIV, human rights, key populations, stigma reduction, non-discrimination, gender sensitization and ethics.
- 4.2 Support is needed to strengthen skills and create spaces for diverse representatives of communities most affected by HIV-related stigma to meaningfully engage, influence, advocate and participate in decision making for programme development in different countries.
- 4.3 The efforts of the Global Partnership are important in bringing together different stakeholders at country-level to develop plans to tackle stigma, led by government and civil society.
- 5. Community leadership in HIV-related stigma-reduction implementation
- 5.1 A combined community-led approach of providing education, counselling, facilitating access to an HIV specialist, and engaging a support person should be scaled up globally within stigma-reduction programming.
- 5.2 It is important that community-led approaches are well documented.
- 5.3 Standard reporting guidelines should be developed on community engagement in HIV-related stigma reduction implementation.
- 5.4 Conceptual frameworks are useful in research, real-world intervention development, and policy on health-related stigmas.

### 6. Intersectional stigma and discrimination

- 6.1 Interventions should endeavour to target a combination of structural-level and individual-level risks and resilience to tackle internalized stigma.
- 6.2 More must be done to protect people who belong to more than one marginalized group from violence, but such laws must be actively enforced, and reporting systems must be available to report abuse and seek redress.
- 6.3 Synergistic attention is required in the areas of internalized stigma and stigma and discrimination within healthcare settings.
- 6.4 Do you agree that a stronger focus is needed on policy-level interventions to address stigma at the institutional and structural levels?

#### 7. HIV-related stigma measures and assessment scales

- 7.1 It is important for researchers and programmers to use validated measures for monitoring and evaluation of stigma- and discrimination-reduction efforts.
- 7.2 It is important for researchers and programmers to use community-led measures for monitoring and evaluation of stigma- and discrimination-reduction efforts.
- 7.3 It is important to adapt existing standardized stigma instruments/measures to specific cultural contexts.
- 7.4 The Stigma Index 2.0, designed by the community for the community, measures multiple types of stigmas and should be better represented in the published literature.
- 7.5 It would be helpful to have guidance on local adaptation of measures.
- 7.6 Additional effort is needed to measure and evaluate the implications of discriminatory laws and the mechanisms of their impact at the individual and health systems levels.
- 7.7 It is important that community organizations implementing the Stigma Index are supported to disseminate their findings in the peer-reviewed literature (e.g., through training about how the data can be analyzed/interpreted in different settings)

#### 8. Monitoring and evaluation (M&E)

8.1 Many countries do not have a robust monitoring and evaluation approach to capture stigma and discrimination – they should be supported to develop one.

# 9. Stakeholder and community participation in M&E

- 9.1 Experiences of stigma should be monitored by community-led organizations.
- 9.2 Efforts must be scaled up to enable communities to monitor experiences of stigma, advocate for change as needed, and engage and lead in programme and policy development.
- 9.3 Community-led efforts must be increased to monitor stigma, discrimination and rights violations.

# 10. Knowledge gaps and research needs

- 10.1 It is important that investment is made to establish a robust evidence base across a range of settings and diverse populations of promising interventions and processes to support stigma reduction.
- 10.2 There is a need to develop and evaluate more diverse approaches to the effectiveness of stigma- and discrimination-reduction efforts
- 10.3 More community-led research is needed about, by and for diverse communities of people living with and affected by HIV, including young people in low- and middle-income countries.
- 10.4 Efforts should be stepped up to strengthen the evidence and knowledge base on stigma and discrimination in law and policy, especially understanding and responding to the extent to which laws are understood in different settings.
- 10.5 Stigma-reduction efforts globally would be better served by including broader outcomes, such as well-being, mental health, quality of life and flourishing.
- 10.6 Research is needed to inform the knowledge gap on the measurement and evaluation of the effectiveness of interventions to address internalized stigma.
- 10.7 It is important that research be conducted to provide data to support future funding investment in the large number of societal enabling approaches that have been piloted and found to positively influence the effectiveness of HIV services.

# 11. Funding to address HIV-related stigma

- 11.1 It would be useful to regularly review the global funding landscape situation in relation to stigma.
- 11.2 It would be useful to review and coordinate national funding landscapes in relation to stigma.
- 11.3 It is important that organizations should track and report their stigma-reduction investments.
- 11.4 It is important to separately track investments in HIV-related stigma and discrimination within broader HIV investments.
- 11.5 It is important to rectify the global funding landscape that is insufficient to meet societal enabler targets.
- 11.6 It is important for major donors to obtain guidance to incorporate due attention to stigma within investments and specific grant allocations.
- 11.7 It is important for major donors to ensure that diverse and inclusive community engagement is considered to guide investment priorities and/or dissemination of results from investments.
- 11.8 It is important for major donors to advocate for and convene other funders to enhance investment in stigma and discrimination-reduction efforts.
- 11.9 Efforts are needed to explore opportunities for long-term stigma- and discrimination-reduction investments.
- 11.10 Means must be determined to provide flexible funding mechanisms that could respond to emerging critical issues
- 11.11 Efforts are needed to integrate stigma and discrimination reduction within investments and strengthen tracking and reporting.

#### 12. Commitment calls

- 12.1 For countries to make concerted efforts to achieve UNAIDS 95-95-95 targets for HIV testing, treatment and viral suppression rates by 2030, commitment is called for to address HIV-related stigma, remove societal and legal impediments to HIV service, scale up treatment and prevention, and improve social conditions.
- 12.2 Strong political and financial commitment is called for to remove the societal and legal impediments that inhibit quality HIV prevention, care, treatment and support services. This is essential for countries to reach their new societal enabler global targets by 2025.
- 12.3 Countries are called upon to commit to specific goals, such as removing legal environments that impede HIV services, and ensuring that no more than 10% of people living with HIV and people in key populations experience stigma and discrimination.
- 12.4 High-level commitment is called for to scale up and improve the quality of programmes to reduce human rights-related barriers to HIV services by mainstreaming lessons learnt from the Breaking Down Barriers initiative across the Global Fund portfolio.
- 12.5 All countries are called upon to invest in societal enabling approaches that remove legal barriers, shift harmful social and gender norms, reduce inequalities and improve institutional and community structures
- 12.6 Countries should commit to removing and/or updating laws that impede HIV services and ensuring that no more than 10% of people living with HIV and people in key populations experience stigma and discrimination.
- 12.7 All countries are called upon to learn about what works and does not work in the 20 countries supported by the Global Fund as part of its Breaking Down Barriers initiative and adopt country-owned strategic plans to reduce human rights-related barriers to services.
- 12.8 Co-action across development sectors is called for to support the three critical enablers of the HIV response- society, systems and services to ensure that HIV services are non-discriminatory and personcentred. These are critical for stigma reduction and achieving national HIV goals.
- 12.9 National governments, research funders and development agencies are called upon to adequately fund the development of evidence-based strategies to reduce HIV-related stigma and discrimination at scale.

# Acknowledging the following consensus points that:

- Addressing HIV-related stigma is important at scale moving beyond individual and facility interventions.
- Achieving consensus on definitions and use of stigma-related language is important.
- Synergistic attention is required in the areas of stigma and discrimination within healthcare settings
  and the resulting stigma (internalized, anticipated and experienced) for people living with HIV and key
  populations.
- Additional effort is needed to measure and evaluate the implications of discriminatory laws and the mechanisms of their impact at the individual and health systems levels.

Acknowledging that communities of people living with HIV in their diversity are at the centre of anti-stigma efforts and must be sustainably and adequately resourced by other stakeholders to lead in:

- Monitoring, reporting, and publishing research by and for diverse communities of people living with HIV, including young people on the experiences of HIV-related stigma, using tools, enable comparability, cross-setting learning and progress assessment toward global targets, including regular implementation of the PLHIV Stigma Index.
- Advocating for increased funding and attention by government, donors, international organizations, and researchers to increase monitoring of, and response systems for, stigma, discrimination and human rights violations
- Steering the design, development and implementation of stigma research projects that are led by noncommunity actors. Documenting community-led approaches to stigma measurement and interventions for learning, adaptation and application in other contexts.

In addition, with the engagement of community-led organizations, we call for the following actors to take heed of this consensus statement and commit to the following actions:

# For researchers:

- 1. Systematically measure stigma to help meet global HIV targets.
- 2. Utilize validated measures for monitoring and evaluation of efforts to reduce stigma and discrimination.
- 3. Develop and evaluate diverse approaches to respond to evolving contexts and learning across disciplines on stigma and new and emerging themes and terminology.
- 4. Adapt existing standardized stigma instruments/measures to specific cultural contexts, for example, translating into appropriate terminology and local languages.
- 5. Incorporate research frameworks based on underlying stigmatization processes and how they manifest.
- 6. Strengthen the evidence base on structural stigma, such as the role of law and policy, especially how laws are understood and interpreted in different settings.
- 7. Strengthen research on the measurement and evaluation of the effectiveness of interventions to address internalized stigma.
- 8. Conduct research to provide costing data to support future funding investment in the large number of societal enabling approaches that have been piloted and found to positively influence the effectiveness of HIV services
- 9. Enable more community-led and authored research in low- and middle-income countries, including supporting community-led organizations implementing the Stigma Index to disseminate their findings in the peer-reviewed literature (For example, through training about how the data can be analyzed and interpreted in different settings).

# For health policy planners and medical schools:

- 1. Train medical students and healthcare providers on HIV, human rights, inclusion and diversity, stigma reduction, non-discrimination, gender sensitization and ethics in all pre-service and in-service professional education.
- 2. Develop and disseminate guidance on local adaptation of measures.
- 3. Develop and disseminate standard reporting guidelines on community engagement.

# For implementers:

- 1. Ensure that there are spaces that enable diverse community leadership, taking intersectionality into consideration, ensuring that communities can meaningfully engage, influence, advocate and participate in decision making for programme development in different countries.
- Combine community-led approaches of providing education, counselling, facilitating access to HIV specialist advice and engaging a support person to scale up stigma-reduction programming.
- Interventions should endeavour to target a combination of structural-level and individual-level risks and resilience to tackle internalized stigma.
- 4. Diversify approaches for tackling stigma and discrimination beyond education and counselling.
- 5. Track investments in HIV-related stigma and discrimination within broader HIV investments.
- 6. Offer support to networks implementing the Stigma Index 2.0 to disseminate their findings in the peer-reviewed literature.

#### For funders:

- Support countries to develop robust monitoring and evaluation approaches to capture stigma and discrimination.
- 2. Ensure that diverse and inclusive community engagement is considered to guide investment priorities and/or dissemination of results from investments.
- 3. Invest in establishing a robust evidence base across a range of settings and diverse populations of promising interventions and processes to support stigma reduction.
- 4. Resource communities to monitor experiences of stigma, advocate for change as needed, and engage and lead in programme and policy development.
- 5. Regularly review the global funding landscape situation in relation to stigma.
- 6. Review and coordinate national funding landscapes in relation to stigma.
- 7. Obtain guidance to incorporate due attention to stigma within investments and specific grant allocations.
- 8. Track and report funders' stigma-reduction investments.
- Integrate stigma and discrimination reduction within investments and strengthen tracking and reporting.
- 10. Separately track investments in HIV-related stigma and discrimination within broader HIV investments.
- 11. Strengthen the global funding landscape to meet societal enabler targets.
- 12. Advocate for and convene other funders to enhance investment in stigma- and discrimination-reduction efforts.
- 13. Invest in longer-term strategies to address stigma and discrimination and evaluate progress over time.
- 14. Provide flexible funding mechanisms to respond to emerging critical issues, evolving contexts and learning across disciplines.

# For policy makers and duty bearers:

- 1. Lead and support actions to reduce stigma and discrimination, including through the Global Partnership to eliminate HIV-related stigma.
- 2. Do more to protect people who belong to more than one marginalized group from violence, to report abuse and seek redress.
- 3. Develop a robust monitoring and evaluation approach to capture stigma and discrimination.
- 4. Enable communities to monitor experiences of stigma, advocate for change as needed, and engage and lead in programme and policy development.

# Specifically, we call on **all countries and their cross-sectoral leadership** to:

- Make concerted efforts to achieve UNAIDS 95-95-95 targets for HIV testing, treatment and viral suppression by 2030 and commit to addressing HIV-related stigma and removing societal and legal impediments to HIV services, in addition to scaling up treatment and prevention and improving social conditions.
- 2. Commit to specific goals, such as removing legal environments that impede HIV services and ensuring that no more than 10% of people living with HIV and people in key populations experience stigma and discrimination.
- 3. Invest in societal enabling approaches that remove legal barriers, shift harmful social and gender norms, reduce inequalities and improve institutional and community structures.
- 4. Remove and/or update laws that fuel stigma and impede HIV services.