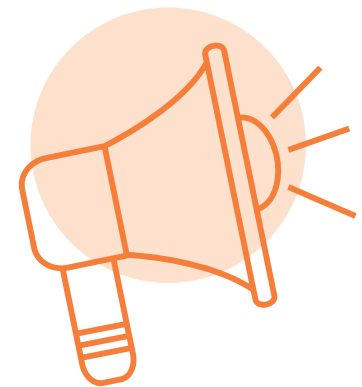




MEASURE IT, ACT ON IT, DO IT: USING THE PLHIV STIGMA INDEX TO ACHIEVE CHANGE



A toolkit to equip networks of people living with HIV to take forward advocacy actions based on key findings and recommendations from PLHIV Stigma Index Reports



Acknowledgements

Writing and editing: Rebekah Webb, Pim Looze and Omar Syarif

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Design: Jane Shepherd

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Abbreviations and acronyms

ACWC	ASEAN Commission for the Promotion and Protection of the Rights of Women and Children	NAFOPHANU	National Forum of People Living with HIV/AIDS Networks in Uganda
ACMW	ASEAN Committee on the Implementation of the ASEAN Declaration on the Protection and Promotion of the Rights of Migrant Workers	NGO	Non-governmental organisation
AICHR	ASEAN Inter-governmental Commission on Human Rights	OAS	Organization of American States
ARASA	AIDS and Rights Alliance for Southern Africa	OHCHR	Human Rights Committee
ASEAN	Association of Southeast Asian Nations	PLHIV	People living with HIV
CAB	Community advisory boards	PWN-USA	Positive Women’s Network-USA
CESCR	Committee on Economic, Social and Cultural Rights	SALC	Southern Africa Litigation Centre
CEDAW	Commission on the Elimination of Discrimination against Women	UN	United Nations
CRC	Commission on the Rights of the Child	UNAIDS	Joint United Nations Programme on HIV and AIDS
CSO	Civil society organisation	UNDP	United Nations Development Programme
GIPA	Greater Involvement of People living with HIV and AIDS	UNESCO	United Nations Educational, Scientific and Cultural Organization
GNP+	Global Network of People Living with HIV	UNFPA	United Nations Population Fund
IACHR	Inter-American Commission on Human Rights	UNYPA	Uganda Network of Young People Living with HIV & AIDS
ICW	International Community of Women Living with HIV	UPR	Universal Periodic Review
ILO	International Labour Organization	VAAC	Vietnamese Authority of AIDS Control
LGBTI	Lesbian, gay, bisexual, transgender and intersex	VNP+	Vietnam Network of People Living with HIV
		ZNNP+	Zimbabwe National Network of People Living with HIV



ADVOCACY = EDUCATION + ACTION!

Introduction: Knowledge = power

Stigma and discrimination against people living with HIV is often talked about, but usually left out of HIV programming and policy. It is thought of as a hazy, intangible thing that is hard to quantify and address. Decision-makers prefer dealing with simple numbers – how many tested, treated and virally suppressed – rather than feelings and social attitudes. Reports of poor treatment are often dismissed as one-off stories or rumours. In addition, people living with HIV often feel too ashamed to report experiences of discrimination against them. Yet without addressing HIV-related stigma and discrimination, the world will not achieve the goal of ending AIDS as a public health threat by 2030.

The People Living with HIV (PLHIV) Stigma Index is a standardised tool to gather evidence on how stigma and discrimination impacts the lives of people living with HIV. It was developed to provide much-needed data and evidence that could be used to advocate for the rights of people living with HIV. Importantly, it was designed to be used by and for people living with HIV and was created to reflect and support the Greater Involvement of People living with HIV and AIDS (GIPA) principle, where PLHIV networks are empowered to lead the whole implementation of the study. The updated and strengthened PLHIV Stigma Index 2.0 (2018) reflects the latest context in the HIV response globally and has now been completed in 10 countries as per March 2020.

For over a decade, the PLHIV Stigma Index has been a catalyst for change in over 100 countries around the world and the results and recommendations used in evidence-driven

advocacy at all levels of the HIV response. National networks of people living with HIV are using Stigma Index Reports creatively in a variety of ways – as a tool for fundraising, community education and anti-stigma campaigns.

PLHIV Stigma Index Reports are already guiding changes to HIV service delivery and informing national health legislation and treatment policy. However, to date they have not been used as fully as they could have been to challenge wider societal and legal norms, or to tackle institutionalised discrimination in the areas of education, workplaces or the justice system.

Why this advocacy toolkit?

The purpose of this advocacy toolkit is to complement and strengthen ongoing work by supporting community advocates to develop advocacy strategies that target discriminatory policies and practices head-on, take ownership



of the advocacy agenda, demand their rights and hold those in power to account.

Specifically, the toolkit has been developed to:

- Provide a set of practical tools that support community advocates to take concrete steps to turn the data and key findings of PLHIV Stigma Index Reports into practical advocacy actions
- Help networks of people living with HIV to identify and take forward advocacy actions based on the key findings and recommendations from PLHIV Stigma Index Reports
- Support Stigma Index teams who are at the data analysis stage of the project or who are in the process of developing reports
- Build the capacity of advocates to use data on stigma to make a case for change



KEY DEFINITIONS

HIV-related stigma is when someone, for example a family member, employer, doctor, or someone you know from work or church views you in a negative way or holds unfair or negative beliefs about you based on your HIV status. Self-stigma is also when you have these negative views or beliefs about yourself.

Discrimination is when someone treats you unfairly based on those negative and unfair views and beliefs.

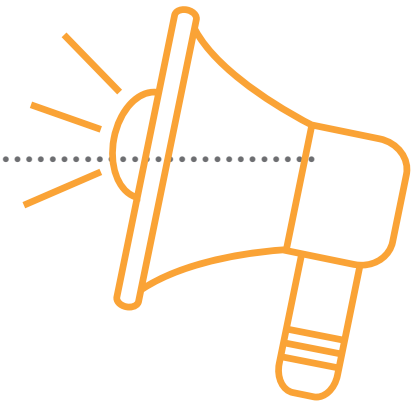
Intersectional discrimination refers to the fact that people living with HIV also experience stigma and discrimination because of groups they belong to, ways they self-identify and things they do. Prejudices such as racism, sexism, homophobia and transphobia all play a role in the worldwide HIV epidemic. The PLHIV Stigma Index 2.0 has been designed to capture the multiple and intersecting layers of stigma and discrimination faced by sex workers, lesbian, bisexual, gay, transgender and intersex (LBGTI) people, and people who use drugs.

What do we mean by advocacy?

Advocacy is a broad term used to refer to many kinds of activities carried out by community organisations and networks that aim to raise awareness and bring social change. An 'advocacy group' is an organised collection of people who use facts, the media and messaging to educate decision-makers and the public.

In this toolkit we focus on advocacy activities that are specifically aimed at changing laws, policy and practice by influencing government officials and those in positions of power. To achieve this, a range of familiar strategies may be needed, such as working with the media, building networks, awareness-raising, holding demonstrations and shifting public opinion. These will support approaches such as engaging directly with parliamentarians and government officials, participating in policy-making bodies and submitting evidence to public consultations and national human rights bodies.

To be successful, a PLHIV Stigma Index advocacy strategy must directly address discrimination by and within political, economic, and social institutions, as much as seek to reduce stigma within the community. It begins by asking, 'what needs to change at the legal and policy level, and who has the power to make those changes'? The end goal of the advocacy strategy must be to challenge harmful policies, laws and practices that enable or promote discrimination. To achieve this, community initiatives must be complemented by targeted advocacy.



Advocacy can have short, medium or long-term goals and continually evolves with the ever-changing world. To be effective, ongoing advocacy capacity and resources will be needed over several years. This toolkit focuses on how to kick-start that process.

EXAMPLE OF A TWIN-TRACK APPROACH

A PLHIV Stigma Index Report reveals that people living with HIV are being arrested and taken to court on charges related to their HIV status. Community networks respond to this by setting up legal support services. However, advocacy strategies must also include efforts to repeal or reform harmful HIV criminalisation laws and strengthen legal frameworks that protect the rights of people living with HIV. Legal aid on its own will not change the situation. A twin-track approach of providing support while also tackling the root cause of the problem is a more effective solution.

Toolkit overview

Advocacy requires both education and action. To be effective, advocacy needs to be based on good evidence, and those in power need to be educated about why change is needed. PLHIV Stigma Index Reports provide the material for the first stage in the process, identifying what needs to change. The second stage is to find out who can make that change.

Timings	Overview	Tools
Stage 1: What needs to change?		
1-2 days	Step 1: Review findings and recommendation	Tool 1: Prioritisation grid Tool 5: Advocacy plan template
2 days including a half-day meeting	Step 2: Convene	Tool 2: Meeting agenda and facilitation notes Tool 5: Advocacy plan template
Stage 2: Who can make that change?		
1-2 days	Step 3: Map opportunities and targets	Tool 3: Using the human rights system Tool 5: Advocacy plan template
1 day	Step 4: Plan	Tool 4: Advocacy budget template Tool 5: Advocacy plan template



Review

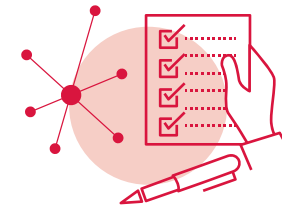
What needs to change?



Convene

What are the most urgent issues to address?

Who are your partners and allies?



Map

What are the key opportunities, targets and goals?



Plan

What are the key dates, activities and costs?

STAGE 1: WHAT NEEDS TO CHANGE?



In this stage you will review PLHIV Stigma Index findings and recommendations and then convene a review meeting with a PLHIV Stigma Index partnership team to prioritise the advocacy actions to focus on.

Step 1: Review findings and recommendations

Step 2: Convene

Step 1: Review findings and recommendations



Estimated time

This work will take 1-2 days to complete.

About this step

Step 1 begins with a review of the evidence you have about the discrimination of people living with HIV from the most recent PLHIV Stigma Index Report, its key findings and recommendations.

Tool 1: Prioritisation grid provides a template for this activity.

Who should do this?

It is best to not assign this task to an external consultant or to one person but to work on it as a group in order to share reflections and ideas.

Materials

- Recent PLHIV Stigma Index Report or past reports
- *Tool 1: Prioritisation grid*
- *Tool 5: Advocacy plan template*

1

One of the best places to start is to look at the report recommendations. These are sometimes grouped by the target audience, for example 'Recommendations for government' or 'Recommendations for policy-makers'. Calling on decision-makers to implement these recommendations can form a strong part of your advocacy strategy and messaging.



TIPS

Even if you don't have a recent report, you can use past reports and the most recent data you have.

If you don't find the data you need contained in the report, you can ask the research team for more information.

2

Make a list of the recommendations that explicitly refer to discrimination. Enter these into the relevant sections of *Tool 5: Advocacy plan template*.

Example of a recommendation that relates directly to discrimination: *Specific measures are also needed to increase the confidentiality of test results; healthcare workers in particular need to ensure that results are not disclosed. (Vietnam, 2015)*

Example of a recommendation that does **not** relate directly to discrimination: *Different communities have diverse needs, which require customised responses (Dominican Republic, 2019)*

3

Next, review the key findings in the main body of the report that relate to discrimination and enter them into the appropriate sections of *Tool 5: Advocacy plan template*. These will flag up where there were significant numbers of people reporting discrimination in these areas, or other significant findings.

The PLHIV Stigma Index 2.0 Questionnaire contains 18 questions or 'data-points' that can be used as evidence of discrimination in the justice system, the workplace, education and healthcare settings. For example, Section B is useful for providing evidence to law enforcement agencies, the police and the judiciary to raise concerns around disclosure, mandatory testing in detention and HIV criminalisation. Throughout the Index are also a set of questions relating to employment (Section C Q16(i) and (j), Section D Q19(c), Section E Q24, Section F Q48(b)) that are useful for working with employment bodies, trade

4

unions and training colleges. Section E focuses on interactions with healthcare services, providing key data on a range of human rights topics including mandatory testing, discriminatory treatment by health workers and denial of health services.

Tool 1: Prioritisation grid summarises the relevant questions from the PLHIV Stigma Index 2.0 Questionnaire according to the relevant areas of the Global Partnership for Action to Eliminate Stigma and Discrimination and provides examples of how these are contraventions of specific rights.

Finally, review the report for key findings relating to other kinds of discrimination, in other words where people are discriminated against disproportionately based on their gender, sexual identity, migration status or behaviour. The Stigma Index 2.0 Questionnaire contains a few questions specifically for women only (e.g. Q47, Q48) but it is also possible to disaggregate the responses by gender or key population to determine if women or men are being treated differently. Enter any significant points into *Tool 5: Advocacy plan template*.

EXAMPLES OF GENDER AND KEY POPULATION-BASED DISCRIMINATION

Dominican Republic: Both women and men reported having a healthcare professional advise them not to have a child in the past 12 months, but this was more common among women (8%) than men (2%).

Uganda: More men compared to women reported that they have never experienced anxiety and depression.

Vietnam: 11.2% of the respondents reported violations of their rights as people living with HIV in the last 12 months. More female sex workers (16.6%) than any other respondents reported such violations, followed by people who inject drugs (15.5%); more women (13.1%) than men (9.6%) reported violations of their rights.

Moldova: In total, 6.1% of respondents have reported that during the last 12 months they have faced at least one of the situations of restriction in achieving basic rights, based on their HIV-positive status. Women, young people and the unemployed are the categories with a higher incidence of such treatments.

CASE STUDY: JUSTICE SYSTEM, MALAWI

In 2017, Malawi proposed an HIV Bill in Parliament that would make HIV testing mandatory for recruitment into some professions and criminalise HIV exposure and transmission. A grassroots network of women living with HIV, alarmed by the implications of this for women who are diagnosed during pregnancy, came together with the support of GNP+ and other legal rights networks to organise consultations with parliamentarians. As a result of their powerful testimony, MPs voted to remove the harmful provisions in the final Bill.

Tool 1: Prioritisation grid

Focus area	PLHIV Stigma Index Questionnaire	Question	How to use it
Justice system	Section B: Question 14 (k)	My HIV status was disclosed to authority figures (police, judges, law enforcement officials, etc.) without my consent	Demand the right to privacy, confidentiality of medical records and HIV status, with penalties for those that flout the law Demand the removal of legislation that permits mandatory HIV testing upon arrest and call for all testing to be voluntary
	Section F: Question 48 (f)	I was arrested or taken to court on a charge related to my HIV status	Demand the repeal of laws that criminalise HIV non-disclosure, exposure and transmission
	Section E: Question 33	I am not taking HIV treatment or stopped because I was in prison or detention and treatment was not available	Demand full access to treatment for incarcerated people
Workplace	Section B: Question 14 (f)	My employer(s) and/or co-workers know my HIV status	Demand the right to workplace confidentiality
	Section B: Question 14 (g)	My HIV status was disclosed to my employer(s) and/or co-workers without my consent	Demand the right to privacy and demand removal of any legislation that permits HIV testing as part of recruitment processes
	Section C: Question 16 (i)	I have been refused employment or lost a source of income or job because of my HIV status	Demand right to equal opportunities and the removal of workplace discrimination against people living with HIV
	Section C: Question 16 (j)	My job description or nature of my job was changed, or I was denied a promotion because of my HIV status	As above
	Section F: Question 48 (b)	I was forced to get tested for HIV or disclose my status in order to apply for a job or get a pension plan	Call for HIV workplace policies and demand removal of any legislation that permits HIV testing as part of recruitment or pension entitlement
Education	Section B: Question 14 (h) & (i)	My teacher(s) and/or school administrators and/or classmates know my HIV status, or my HIV status was disclosed to them without my consent	Demand the right to privacy and confidentiality for all students and pupils
	Section F: Question 48 (c)	I was forced to get tested for HIV or disclose my status in order to attend an educational institution or get a scholarship	Demand the removal of policies that include mandatory testing as part of enrolment or scholarship applications; demand an end to educational discrimination against people living with HIV

Focus area	PLHIV Stigma Index Questionnaire	Question	How to use it
Healthcare	Section E: Question 21	I was tested without my knowledge and only found out after the test had been done I was forced to take an HIV test without my consent	Demand the right to bodily integrity, informed consent and an end to unethical medical practices Demand compliance of all health services with human rights standards
	Section E: Question 27	I felt pressured or forced to start HIV treatment by healthcare staff	Demand informed consent and an end to mandatory treatment
	Section E: Question 33	I stopped care or treatment for HIV and hesitated or delayed restarting care because I had a bad experience with a health worker previously	Demand compliance of all health services with human rights standards
	Section E: Question 41	I have experienced stigma and discrimination from health facility staff where I receive HIV care in the form of: a. Denial of services b. Instruction not to have sex c. Gossip d. Verbal abuse e. Physical abuse f. Avoidance of contact (double-gloving) g. Disclosure without consent	Demand compliance of all health services with human rights standards, including patient confidentiality
	Section E: Question 43	I have experienced stigma and discrimination from non-HIV health facility staff in the form of: a. Denial of services b. Instruction not to have sex c. Gossip d. Verbal abuse e. Physical abuse f. Avoidance of contact (double-gloving) g. Disclosure without consent	Demand compliance of all health services with human rights standards, including patient confidentiality

Focus area	PLHIV Stigma Index Questionnaire	Question	How to use it
Healthcare	Section E: Question 45	It's clear to me that my medical records are not being kept confidential	Demand the right to privacy and patient confidentiality
	Section E: Question 46	Solely due to my HIV status, healthcare professionals have: <ul style="list-style-type: none"> a. Advised me not to have a child b. Pressured or incentivised me to get sterilised c. Sterilised me without my knowledge/consent d. Denied me contraception/FP services e. Told me I had to use a specific method of contraception to get HIV treatment 	Demand the right to informed consent
	Section E: Question 47	(Women-only) Solely due to my HIV status, healthcare professionals have: <ul style="list-style-type: none"> a. Advised me to terminate a pregnancy b. Pressured me to use a specific type of contraception c. Pressured me to use a particular method of giving birth/delivery option d. Pressured me to use a particular infant feeding practice e. Pressured me to take HIV treatment during pregnancy 	Demand sexual and reproductive health rights for women living with HIV Demand the right to informed consent

Step 2: Convene



Estimated time

This work will take two days to complete, including a half-day meeting.

About this step

Step 2 is to convene a half-day meeting with a PLHIV Stigma Index partnership team to present and discuss the findings and recommendations of the report and identify which are the most urgent to address. It is important to do this collectively to build consensus and support for the advocacy strategy.

Who to invite?

Everyone who worked on the PLHIV Stigma Index report, including the research partners, all national networks of people living with HIV, the National AIDS Council, UNAIDS, human rights organisations, development agencies e.g. Action Aid and other close advocacy partners. Be sure to include allies from faith-based, youth, women's and disability rights organisations and networks as well as representatives from key populations in your community.



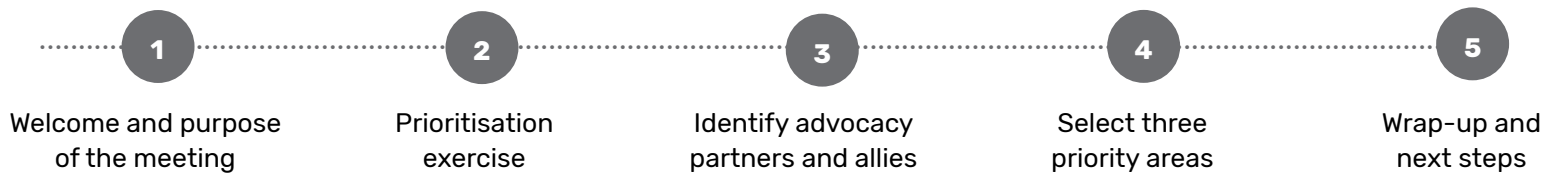
TIP

Ask your invitees to make suggestions of other advocacy partners or allies to invite.

Materials

- *Tool 2: Meeting agenda and facilitation notes.* This tool provides an outline agenda of how your meeting could be structured and how to facilitate it.
- Flipcharts and pens

MEETING AGENDA



Tool 2: Outline agenda and facilitation notes

1

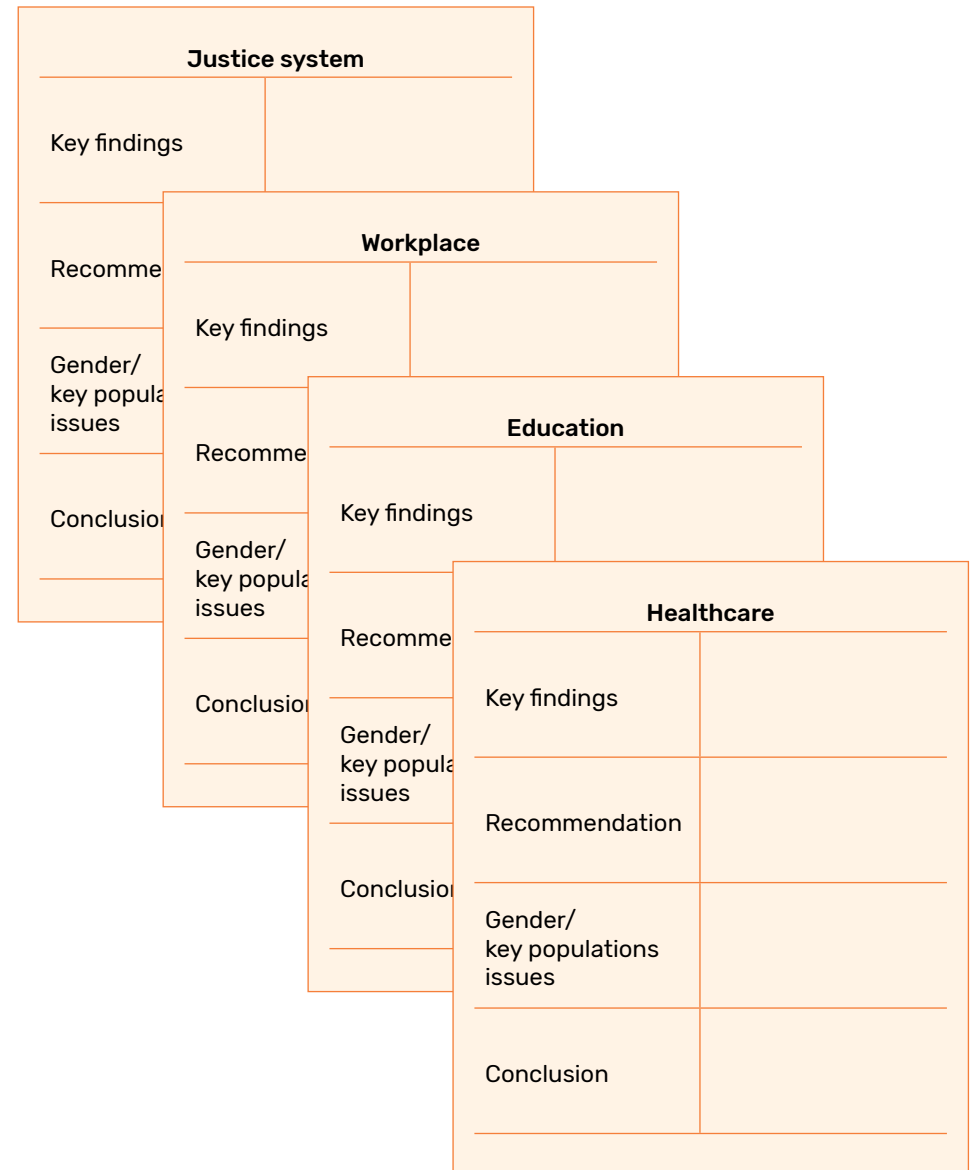
Welcome and purpose of the meeting

- Welcome participants and do a round of introductions.
- Explain the need for a meeting to review the findings of the PLHIV Stigma Index Report that relate to institutional discrimination and to translate these into a concrete advocacy plan. By the end of the meeting, the following should be in place:
 - A list of advocacy actions grouped by discrimination area
 - A decision on three priority areas to take forward
 - A small taskforce who will develop an advocacy plan

2

Prioritisation exercise

- Create a flipchart for each of the four areas
- List the key findings and recommendations by area
- Within each area, prioritise them to get one issue per area and identify one or two issues to take forward
- Present the review that was completed in Step 1 using Tool 1, setting out the report's relevant key findings and recommendations by discrimination area. You can do this using the headings on these flipcharts.
- Having reviewed the key findings, recommendations and gender/ key population issues for each of the four areas, collectively agree on a summary to put in the conclusion row.



3

Identify advocacy partners and allies

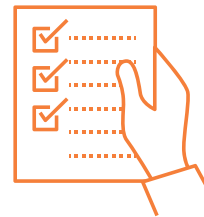
- Create a flipchart using the below partners and allies grid.
- Brainstorm the partners that will be needed and potential allies you can draw on to support your work.

Partners will be community-based organisations and civil society actors that are already active in campaigning and advocating for human rights in the area of discrimination that you are looking at. For example, in the area of the justice

system, you would partner with human rights lawyers and non-governmental organisations (NGOs) specialising in human rights. In education you would partner with student unions and colleges. Allies will include United Nations (UN) organisations specialising in the area you are looking at, for example the International Labour Organization (ILO) in the area of employment discrimination and United Nations Population Fund (UNFPA) in the area of violations against reproductive rights.

	Justice system	Workplace	Education	Healthcare
Partners				
Allies				

4



Select three priority areas

In small groups or in plenary discuss and agree on the top three areas of discrimination that are most urgent to work on, based on the level of importance of the issue and the partners and allies you can bring to the table. Consider whether advocacy actions are achievable within a year, or will take longer to happen.



TIP

In countries that have signed up to the Global Partnership for Action, it is a good idea to select the same three areas of focus that the country has picked.

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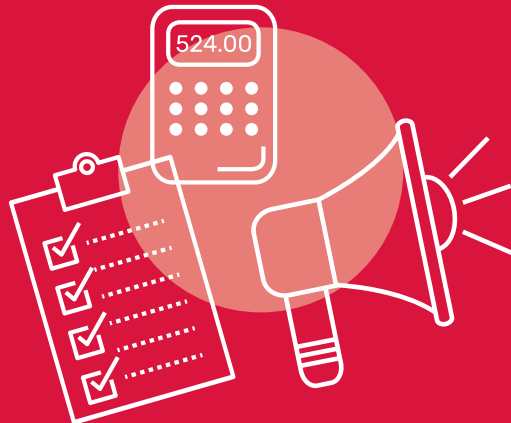
Wrap-up and next steps

Ask for volunteers to be part of a taskforce to develop an advocacy plan based on the three priority areas of action you have selected.

CASE STUDY: CREATIVE STRATEGIES

In 2014, the Uganda Network of Young People Living with HIV/AIDS (UNYPA) was inspired by the results of the first PLHIV Stigma Index study in Uganda to create a national Beauty Pageant for young people living with HIV. Five years on, the pageant has reduced HIV stigma by giving young people a platform for them to express themselves and normalising living with HIV. Now a major media event, the first pageant recruited 10 young people but attracted over 100 contestants in 2019, showing how stigma can be challenged head-on. Additional stigma index studies in the communities where the pageant has been held show a clear reduction in discriminatory attitudes against HIV.

STAGE 2: WHO CAN MAKE THAT CHANGE?



In this stage, the taskforce you set up in Step 2 will map and identify key opportunities, targets and goals for your advocacy and develop an advocacy plan.

Step 3: Map opportunities and targets

Step 4: Plan

Step 3: Map opportunities and targets



Estimated time

This work will take 1–2 days depending on how much experience you have with this kind of advocacy and your existing contacts.

About this step

This step begins with a mapping of who has the power to take steps to end discrimination against people living with HIV in the three priority areas you have selected. It also provides information in *Tool 3: Using the human rights system* on some of the key advocacy spaces at the national, regional and international level in which PLHIV Stigma Index report findings can be raised, shared or submitted as evidence. *Tool 5: Advocacy plan template* provides a template for this activity.

Who should do this?

The taskforce of volunteers from the PLHIV Stigma Index partnership team that you set up at the end of the meeting in Step 2.

Materials

Tool 3: Using the human rights system

Tool 5: Advocacy plan template



TIP

Download *Tool 5: Advocacy plan template* as a Word document. Click on the paperclip in the left-hand column of this PDF.

Tool 3: Using the human rights system

“People living with, at risk of and affected by HIV should enjoy equally all human rights and enjoy equal participation in civil, political, social, economic and cultural life, without prejudice, stigma or discrimination of any kind.”

*United Nations Political Declaration
on Ending AIDS, 2016*

All countries in the world have a legal and moral obligation under the Universal Declaration of Human Rights, international human rights treaties (see below) and the 2030 Agenda for Sustainable Development to remove discriminatory laws and enact laws that protect people from discrimination.

Such rights include the right to privacy, dignity, health, education, economic opportunities and equal treatment before the law. In nations all over the world, laws based on these rights govern workplace rules, parental consent and health and education policy.

The 2016 United Nations Political Declaration on Ending AIDS expressed grave concern that stigma and discrimination continue to be reported and that restrictive legal and policy frameworks continue to exist. Member states committed to ending HIV-related stigma and discrimination by 2020 by:

- Promoting non-discriminatory access to healthcare, employment, education and social services;
- Eliminating gender inequalities and ending all forms of violence and discrimination against women and girls;
- Reviewing and reforming laws that reinforce stigma and discrimination, including age of consent, HIV non-disclosure, exposure and transmission, travel restrictions and mandatory testing; and
- Empowering people living with, at risk of or affected by HIV, to know their rights and access justice and legal services.

In this section we review structures at international, regional and national level that are important for advocacy on HIV discrimination and look at easy ways to submit, share and raise data and key findings from PLHIV Stigma Reports with key human rights bodies.

International human rights treaty bodies

There are nine core international human rights treaties (also known as international human rights instruments). These include:

- International Covenant on Civil and Political Rights (1966)
- International Covenant on Economic, Social and Cultural Rights (1966) and

- Convention on the Elimination of All Forms of Discrimination against Women (1979).

The implementation of these treaties is monitored by corresponding human rights treaty bodies, such as the Human Rights Committee (OHCHR), the Commission on the Rights of the Child (CRC) and the Commission on the Elimination of Discrimination against Women (CEDAW). These are international committees of 20 or so independent experts who meet every year to review reports from countries on how they are implementing the rights of the Conventions and Covenants. During annual sessions the Committees consider each government report and address concerns and recommendations to the government in the form of concluding observations. Treaty bodies also have the power to consider individual complaints.

What are shadow reports?

Each treaty body has a process by which civil society can submit evidence to them for consideration, to supplement the formal report submitted by the government. These are known as ‘alternative reports’, or ‘shadow reports’. You can also apply to participate in meetings where human rights issues are discussed to address the committee in person. It is important to follow the rules set out by each treaty body on how to do this as they may differ. In the section below the main treaty bodies are described, with links to their website where you can find out more.

**TIP**

If you are thinking of submitting a shadow report, it is a good idea to partner with civil society organisations (CSOs) that are already familiar with the process and to adhere to the guidelines for submission provided by the relevant Committee.

CASE STUDY: KAZAKHSTAN

In 2019, a coalition of people living with HIV networks and CSOs in Kazakhstan developed a shadow report on discrimination and violence against women who use drugs, women living with HIV, sex workers and women in prison to highlight government inaction on delivering the National Plan against Stigma and Discrimination for 2018–2019. They included statistics from the 2015 PLHIV Stigma Index Report on the high numbers of women living with HIV that had experienced forced abortions from medical personnel and who had never received counselling on reproductive health. The shadow report was presented by women living with HIV at the CEDAW meeting in March 2019 and led to the CEDAW Committee including specific language on discrimination against women living with HIV and women who use drugs in their formal list of issues and questions to the government.

Human Rights Committee

Human Rights Committee is the body of independent experts that monitors implementation of the International Covenant on Civil and Political Rights. All member countries are obliged to submit regular reports to the Committee on how the rights are being implemented. Governments must report initially one year after acceding to the Covenant and then every four years. The Committee examines each report and addresses its concerns and recommendations to governments in the form of "concluding observations". To learn more about the schedule of meetings, the Centre for Civil and Political Rights provides a useful [guide](#).

Committee on the Elimination of Discrimination Against Women

Adopted in 1979, **CEDAW** covers almost all areas of discrimination against women including health, sex work and education. As with the Human Rights Committee, all countries that have signed the Convention have to submit initial and periodic reports on its implementation every four years. The CEDAW Committee consists of 23 independent experts. To influence the findings of the Committee, civil society can submit shadow reports that give an alternative perspective from the grassroots, or even participate in session working groups. These can then be included in the recommendations given to governments (known as concluding observations). The CEDAW portal by the International Women's Rights Action Watch

Asia Pacific (IWRAW-AP) provides an excellent [guide](#) to the process.

Committee on Economic, Social and Cultural Rights

The **Committee on Economic, Social and Cultural Rights** (CESCR) is the body of 18 independent experts that monitors national implementation of the International Covenant on Economic, Social and Cultural Rights. The Committee meets in Geneva and welcomes written information, which should be as specific, reliable and objective as possible, from national and local organisations. Parallel submissions (shadow reports) prepared by coalitions, rather than individual organisations, and covering a broad range of economic, social and cultural rights are also encouraged.

Universal Periodic Review

Every four years, each of the 193 member states of the UN is reviewed on its entire human rights record. Most of the process takes place at the national level. The **Universal Periodic Review** (UPR) process provides for the participation of all relevant stakeholders, including NGOs, national human rights institutions and regional mechanisms, who can submit written information for the report. Accredited stakeholders can attend and observe the session of the UPR Working Group and make oral statements during the regular sessions of the Human Rights Council when the outcomes of the government reviews are considered. You can find details of the process [here](#).

**TIP**

At any point in time, it is very likely that your country will be under review by at least one human rights committee. To find out when your country is coming up for review, consult the calendar of the relevant committee on their website (usually described as the 'schedule').

CASE STUDY: GHANA

Ghana's human rights record was reviewed by the UN in 2017. To contribute to the UPR Working Group assessment, the Ghana Human Rights NGO Forum produced a *Factsheet on HIV Stigma and Discrimination* calling for full implementation and strict enforcement of the AIDS Commission Act 2016 providing full protection to persons with HIV. The Forum included the *2013 PLHIV Stigma Index Report* as evidence of why action was urgently needed. The factsheet can be viewed [here](#).

Regional human rights bodies

Most of the regions of the world have a regional instrument to support the promotion and protection of human rights, although they don't all work in the same way. The way that civil society can participate and influence these regional bodies varies, so it is important to check their website.

African Commission on Human and Peoples' Rights

The **African Commission on Human and Peoples' Rights** is composed of 11 independent human rights experts, nominated by member governments and elected by the Assembly, holding its ordinary sessions twice a year in Banjul or in another African capital. The Commission also oversees implementation of the African Youth Charter.

Africa Women's Protocol

The **Africa Women's Protocol** (Maputo Protocol) is a type of women's rights charter. It arose partly as a result of the failure of the African Charter on Human and People's Rights to address women's rights. It guarantees comprehensive rights to women including the right to take part in the political process, to social and political equality with men and improved autonomy in their reproductive health decisions. The Maputo Protocol has not yet been signed by Botswana, Egypt or Morocco.

African Committee on the Rights and Welfare of the Child

This **African Committee on the Rights and Welfare of the Child** was established to monitor government compliance with the African Charter on the Rights and Welfare of the Child adopted in 1990. In Africa the rights extend to all those below the age of 18 without exception.

ASEAN Intergovernmental Commission on Human Rights

The **ASEAN Intergovernmental Commission on Human Rights** (AICHR) was set up as the overarching body to promote and protect human rights in the Association of Southeast Asian Nations (ASEAN) region. Two sectoral bodies working on human rights have also appeared: the ASEAN Commission for the Promotion and Protection of the Rights of Women and Children (ACWC) and the ASEAN Committee on the Implementation of the ASEAN Declaration on the Protection and Promotion of the Rights of Migrant Workers (ACMW).

Asia Pacific Forum

The **Asia Pacific Forum** provides an umbrella under which 17 national Human Rights Institutions convene and plays a major role promoting and protecting human rights. This is the closest that the Asia-Pacific region has to a regional instrument because the sub-regional mechanism of the ASEAN is a rather weak instrument.

Inter-American Commission on Human Rights

The mission of the **Inter-American Commission on Human Rights** (IACHR) is to promote and protect human rights in the American hemisphere and to serve as a consultative organ of the Organization of American States (OAS). The IACHR is composed of seven independent members who serve in a personal capacity. The work of the

IACHR rests on three main pillars: the individual petition system; monitoring of the human rights situation in the member states; and the attention devoted to priority thematic areas. Created by the OAS in 1959, the IACHR has its headquarters in Washington, D.C.



TIP

Find out which NGOs and advocacy partners sit on these regional bodies as observers. For example, the AIDS and Rights Alliance for Southern

Africa (ARASA) is an Observer at the African Commission on Human and Peoples' Rights.

National human rights institutions

Globally, there are around 65 national human rights institutions, with some more established and effective than others. Their role is to advise governments on the implementation of international human rights obligations, recommend law reform, carry out investigations into human rights abuses, handle complaints and educate the public on their human rights.

Example: In Argentina, the National Institute against Discrimination, Racism and Xenophobia collects data on experiences of discrimination on the basis of HIV status, sexual orientation, gender identity, socioeconomic status, skin colour and other characteristics and publishes a discrimination map that inform efforts to eliminate discrimination.



TIP

To find out if your country has a national human rights institution, check this list on the OHCHR website.

CABS and tribunals

Community advisory boards (CABs) and tribunals are increasingly important spaces for people living with HIV to report human rights violations. In Swaziland a toll-free line and suggestion boxes placed at facilities generate reports that go to the Ministry of Health, while in Kazakhstan and Ukraine, CABs bring together people affected by discrimination and representatives of health authorities. In 2006, Kenya set up the world's only HIV-specific statutory body: the HIV and AIDS Tribunal.

CASE STUDY: VIETNAM

The PLHIV Stigma Index study conducted in Vietnam in 2014 found high rates of many types of stigma and discrimination against people living with HIV. The Vietnam Network of People Living with HIV (VNP+) successfully used the findings to influence Ministry of Health guidelines for strengthening activities to reduce stigma and discrimination related to HIV in healthcare facilities.

A survey of stigma and discrimination in healthcare was conducted by the Ministry of Health in Ho Chi Minh City in late 2016, with what the Vietnamese Authority of AIDS Control (VAAC) described as 'eye-opening' results. 73% of healthcare workers surveyed reported a fear of HIV infection via routine care for people living with HIV and 60% of people living with HIV reported a fear that their medical records would not be kept confidential.

Working closely with the community, VAAC and VNP+ conducted a pilot project to engage the community with healthcare worker training and set up a CAB in Binh Duong. After nine months of the community interventions in Binh Duong, fear of HIV infection had considerably subsided among healthcare workers and reported experiences of discrimination were down from 25% to 15%.

Step 4: Plan



Estimated time

This work will take 1 day.

About this step

When you have identified the key policy processes and people you need to target, you are ready to develop an advocacy plan.

Who should do this?

The network of people living with HIV should lead the planning with support from local partners.

Materials

Tool 4: Sample advocacy budget

Tool 5: Advocacy plan template



TIP

Your advocacy plan is not a fixed document but will evolve over time as you engage with decision-makers and make progress.

Plan key dates and activities

If you have completed each section of Tool 5 you will already have most of the work done in order to plot key dates and activities.

Advocacy capacity

As part of your planning ensure that you take into account the resources you need to complete your activities.

To undertake advocacy activities related to the PLHIV Stigma Index it is recommended that you have at least a part-time or full-time experienced staff member dedicated to advocacy for at least a year following the completion of the report.

You will also need to consider funding for transport, communications, publications, campaigns and events. The template in *Tool 4: Sample advocacy budget* sets out what an advocacy budget for the first year could look like.

Tool 4: Sample advocacy budget

Item	Description	Cost (enter your standard unit costs here)
1.	Salary for advocacy staff for one year following completion of report	
2.	Stakeholder meeting	
	Meeting venue cost	
	Meeting supplies	
	Participant transport	
	Facilitator fee	
	Rapporteur fee	
3.	Meetings with policymakers	
	Transport expenses	
	Airtime/data	
4.	Publications/website	
	Website upgrade	
	Design, layout and printing	
5.	Campaign events/communications	
Total		

Tool 5: Advocacy plan template

	Justice system	Workplace	Education	Healthcare
Stage 1: What needs to change?				
<p>Key findings from the report</p> <p>List the findings by each of the four areas</p>	<p>e.g. Numbers of people living with HIV reporting that they have been arrested</p> <p>See Section B</p> <p><i>The Constitution outlaws discrimination against people living with HIV and AIDS. (Namibia 2018)</i></p>	<p>e.g. Numbers of people being forced to test for employment</p> <p>e.g. Findings reveal that some people living with HIV have lost their jobs due to being HIV-positive</p> <p>See Sections C. 16(i) and (j); D. 19(c); E. 24; F. 48(b)</p>	<p>e.g. Numbers of people being forced to test to attend an educational institution or get a scholarship</p> <p><i>Places of work were identified as some of the leading perpetrators of stigma and discrimination among people living with HIV in Namibia. The Ministry of Labour should spearhead the promotion of equal opportunities for all by sensitising employers and employees on the values of having people employed on merit and not HIV status.</i></p> <p>See Section F. (c)</p>	<p>e.g. Numbers of people being forced to test</p> <p><i>Most nursing homes in South Korea tend to refuse the admission of patients with HIV. (South Korea 2017)</i></p> <p>See Section E.</p>
<p>Gender/Key population issues</p> <p>Note here any key findings relating to human rights abuses of key populations or gender disparities</p>	<p>e.g. Higher numbers of women being arrested compared with men</p> <p><i>Female sex workers seemed particularly vulnerable, with 5.9% reporting having to move or being unable to rent a home, and 3.6% being denied healthcare services. (Vietnam 2014)</i></p>	<p>e.g. Higher numbers of young people and women unemployed</p> <p><i>More than the half of total respondents also reported that they (...) gave up pursuing further education because of their HIV status. (South Korea 2017)</i></p>	<p>e.g. Higher numbers of young men asked to test to get a scholarship</p> <p><i>Men who sex with men living with HIV reported very levels of verbal harassment (83%). (Cameroon, 2018)</i></p>	<p>e.g. People who use drugs experiencing higher levels of discrimination from healthcare workers than other groups</p>

	Justice system	Workplace	Education	Healthcare
<p>Recommendations from the report</p> <p>Add the relevant recommendations here</p>	<p><i>e.g. Legal personnel should be included in trainings and seminars on information on HIV and in other HIV-related information-sharing workshops. (Papua New Guinea 2016)</i></p> <p><i>Strengthen the legal and institutional frameworks for enforcement of the rights of people living with HIV. This should include enactment of the pending HIV bills and the relevant institutions expected to enforce the rights of people living with HIV should be empowered to implement the acts. (Somalia 2017)</i></p> <p><i>The current AIDS Prevention Law that prohibits and criminalises HIV transmission must be amended. Such penalising approach does not only undermine the sexual self-determination of people living with HIV but also perpetuates HIV stigma. (South Korea 2017)</i></p>	<p><i>e.g. Ministry of Gender, Labour and Social Development should oversee implementation of policies related to employment and workplace in regard to HIV. (Uganda 2019)</i></p>	<p><i>e.g. Local authorities must ensure compliance with the existing legal provisions that provide protection for people living with HIV, in particular regarding rights to employment and education, through educational measures that target the community and workplaces and through consistent application of legal sanctions. (Vietnam 2014)</i></p>	<p><i>e.g. Ministry of Health should: review and continuously adapt pre- and in-service training curricula to enhance the capacity of health service providers to offer tolerant and non-discriminatory services to people living with HIV. (Moldova 2018)</i></p>
<p>Conclusion</p> <p>Select the top issue for each area and the 1-2 issues you will prioritise this year</p>				

	Justice system	Workplace	Education	Healthcare
Who can be your partners and allies?				
Stakeholders List the people you will need to work with to achieve change – advocacy partners and allies	e.g. Human rights lawyers, human rights organisations, law schools, law societies	e.g. Employment bodies, trade unions and training colleges	e.g. Universities, colleges and high schools	e.g. Medical schools
Advocacy partners What partnerships will you need to build?	e.g. ICW, ARASA, Southern Africa Litigation Centre (SALC), SERO Project, Positive Women’s Network-USA (PWN-USA), Canadian Legal HIV/AIDS Network, HIV Justice Worldwide national members		e.g. Student unions	e.g. Women’s health advocates, sex worker unions, LGBTI networks
Allies Who can you ask for support and advice?	e.g. United Nations Development Programme (UNDP), MPs	e.g. ILO	e.g. United Nations Educational, Scientific and Cultural Organization (UNESCO)	e.g. UNAIDS, UNFPA
Stage 2: Who can make that change? Who are you going to target and when?				
Targets Who has the power to make change?	e.g. National Human Rights Commissions, International Human Rights Treaty Bodies and Regional Human Rights instruments	e.g. Ministry of Labour/ Department of Work and Pensions	e.g. Ministry of Education	e.g. Ministry of Health, National AIDS Councils, Technical Working Groups on HIV

	Justice system	Workplace	Education	Healthcare
<p>Opportunities</p> <p>What national processes are open for influence? e.g. National Strategic Plan is up for review/ your country is due to report to CEDAW</p> <p>Map the key advocacy spaces at national and regional level at which data from the report can be raised, shared or submitted as evidence</p> <p>Include key dates of events and mechanisms if known</p>	<p>e.g. UPR; African Charter on Human and People’s Rights; Kenya’s HIV/AIDS Tribunal; draft legislation/ legal reform</p>	<p>e.g. Human Rights Committee; AICHR; CESCR</p>	<p>e.g. UNESCO Global Monitoring Report</p>	<p>e.g. National Strategic Plan target setting; World Health Assembly; CABS</p>
How?				
What is the message?				
Who will deliver the message?				
Which of your champions are open to this issue? e.g. you know an MP on the Education Committee/you have a connection to a medical school				
What resources will you need?				

Further reading

JUSTICE

UNAIDS (2019) **Act To Change Laws That Discriminate.**

https://www.unaids.org/sites/default/files/media_asset/2019_ZeroDiscrimination_Brochure_en.pdf

HIV Justice Network (2019) **Advancing HIV Justice 3: Growing the Global Movement Against HIV Criminalisation.** Available in English, French, Russian, Spanish. <http://www.hivjustice.net/advancing3/>

WORKPLACE

GNP+ (2018) **Evidence Brief: HIV Stigma and Discrimination in the World of Work: Findings from the People Living with HIV Stigma Index.**

https://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/documents/publication/wcms_635293.pdf

ILO (2010) **Toolkit for Trade Unions on HIV and AIDS. Booklet 2: Respect for rights: the key to labour and workplace responses.**

https://www.ilo.org/wcmsp5/groups/public/---ed_dialogue/---actrav/documents/publication/wcms_154431.pdf

EDUCATION

UNESCO (2008) **HIV and AIDS and supportive learning environments.**

<https://unesdoc.unesco.org/ark:/48223/pf0000146122>

HEALTHCARE

UNAIDS (2017) **Confronting discrimination Overcoming HIV-related stigma and discrimination in healthcare settings and beyond.**

https://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf

UNAIDS (2017) **Background Note: Zero Discrimination in Health Settings.**

https://www.unaids.org/sites/default/files/media_asset/20171117_UNAIDS_PCB41_Zero_discrimination-health-care-settings_17.27_EN.PDF

HUMAN RIGHTS ADVOCACY

Global Partnership for Action to Eliminate all forms of HIV-related Stigma and Discrimination. https://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf

UNAIDS (2018) **Miles to Go: closing gaps, breaking barriers, righting injustices. Global AIDS Update 2018.**

<https://www.unaids.org/en/resources/documents/2018/global-aids-update>

UN Human Rights Council **Participation in the Reporting Process:**

Guidelines for NGOs. http://ccprcentre.org/files/media/NGO_Guidelines_English1.pdf

The Role of Civil Society Organizations in Monitoring the Global AIDS Response. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5706462/>

PLHIV STIGMA INDEX

PLHIV Stigma Index <https://www.stigmaindex.org/>

Measuring intersecting stigma among key populations living with HIV: implementing the people living with HIV Stigma Index 2.0.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6055043/>

MEASURE IT, ACT ON IT, DO IT





The People Living with HIV Stigma Index
www.stigmaindex.org