

HIV Stigma and Discrimination

Stigma.jpg



HIV-related stigma and discrimination refers to prejudice, negative attitudes and abuse directed at people living with HIV and AIDS. In 35% of countries with available data, over 50% of people report having discriminatory attitudes towards people living with HIV.¹

Stigma and discrimination also makes people vulnerable to HIV. Those most at risk to HIV (key affected populations) continue to face stigma and discrimination based on their actual or perceived health status, race, socioeconomic status, age, sex, sexual orientation or gender identity or other grounds.²

Stigma and discrimination manifests itself in many ways. Discrimination and other human rights violations may occur in health care settings, barring people from accessing health services or enjoying quality health care.³ Some people living with HIV and other key affected populations are shunned by family, peers and the wider community, while others face poor treatment in educational and work settings, erosion of their rights, and psychological damage. These all limit access to HIV testing, treatment and other HIV services.^{4 5}

The People Living with HIV Stigma Index documents the experiences of people living with HIV. As of 2015, more than 70 countries were using the HIV Stigma Index, more than 1,400 people living with HIV had been trained as interviewers, and over 70,000 people with HIV have been interviewed.⁶ Findings from 50 countries, indicate that roughly one in every eight people living with HIV is being denied health services because of stigma and discrimination.⁷

Why is there stigma around HIV and AIDS?

Whenever AIDS has won, stigma, shame, distrust, discrimination and apathy was on its side. Every time AIDS has been defeated, it

has been because of trust, openness, dialogue between individuals and communities, family support, human solidarity, and the human perseverance to find new paths and solutions.

- *Michel Sidibé, Executive Director of UNAIDS*⁸

The fear surrounding the emerging HIV epidemic in the 1980s largely persists today. At that time, very little was known about how HIV is transmitted, which made people scared of those infected due to fear of contagion.

This fear, coupled with many other reasons, means that lots of people falsely believe:

- HIV and AIDS are always associated with death
- HIV is associated with behaviours that some people disapprove of (such as homosexuality, drug use, sex work or infidelity)
- HIV is only transmitted through sex, which is a taboo subject in some cultures
- HIV infection is the result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished
- inaccurate information about how HIV is transmitted, which creates irrational behaviour and misperceptions of personal risk.⁹

How stigma affects people living with HIV

My daughter refused to go hospital to receive medicines. My daughter died because of the fear of stigmatization and discrimination

- *Patience Eshun from Ghana, who lost her daughter to an AIDS-related illness*¹⁰

HIV-related stigma and discrimination exists worldwide, although it manifests itself differently across countries, communities, religious groups and individuals. In [sub-Saharan Africa](#), for example, heterosexual sex is the main route of infection, which means that HIV-related stigma in this region is mainly focused on infidelity and sex work.¹¹

Research by the International Centre for Research on Women (ICRW) outlines the possible consequences of HIV-related stigma as:

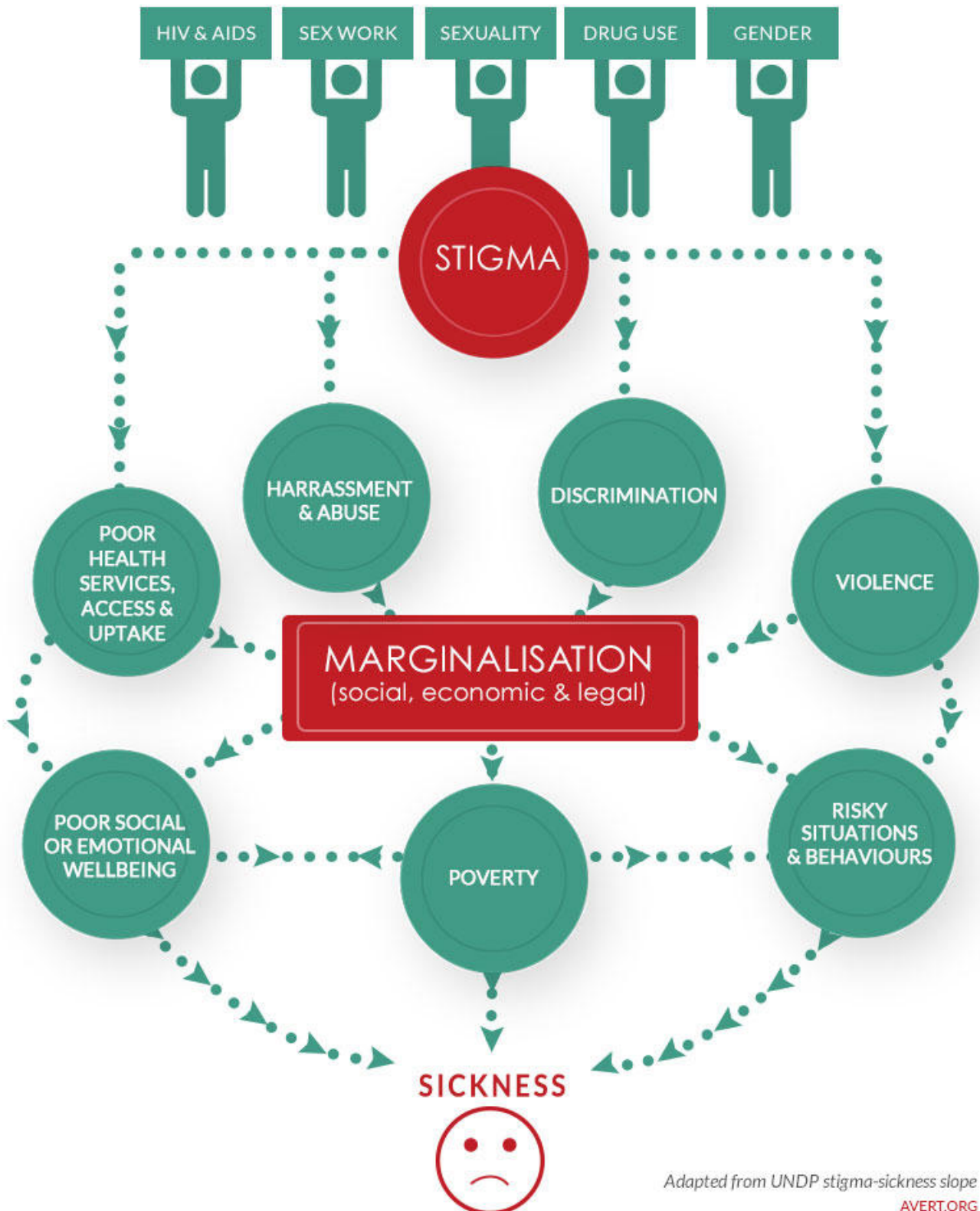
- loss of income and livelihood
- loss of marriage and childbearing options
- poor care within the health sector
- withdrawal of caregiving in the home
- loss of hope and feelings of worthlessness
- loss of reputation.¹²

HIV stigma and key affected populations

Stigma and discrimination is often directed towards [key affected populations](#) such as [men who have sex with men](#) (sometimes referred to as [MSM](#)), [people who inject drugs](#) and [sex workers](#).

HOW STIGMA LEADS TO SICKNESS

Many of the people most vulnerable to HIV face stigma, prejudice and discrimination in their daily lives. This pushes them to the margins of society, where poverty and fear make accessing healthcare and HIV services difficult.



Adapted from UNDP stigma-sickness slope
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These people are increasingly marginalised, not only from society, but from the services they need to protect themselves from HIV. For example, in 2016, 60% of countries in the European Economic Area reported that health care professionals' negative and discriminatory attitudes towards men who have sex with men and people who inject drugs hampered the provision of adequate HIV prevention services for these groups.¹³

More than 90% of new HIV infections in Central Asia, Europe, North America, the Middle East and North Africa in 2014 were among people from key populations and their sexual partners, who accounted for 45% of new HIV infections worldwide in 2015.¹⁴ Recent studies suggest that, globally, people who inject drugs are 24 times more likely to acquire HIV than the general population, sex workers are 10 times more likely and men who have sex with men are 24 times more likely. Moreover, transgender people are 49 times more likely and prisoners are five times more likely to be living with HIV than adults in the general population.¹⁵

WHAT CAN WE DO ABOUT STIGMA ?

An effective response to the HIV epidemic must tackle the root causes of stigma and ensure services are inclusive and accessible.

PROTECT

- Anti-discrimination laws
 - Decriminalisation
 - Challenging violence

INCLUDE

- Key populations in healthcare service design and implementation
- Stigma and discrimination reduction as a goal in national strategies

EMPOWER

- To understand rights
- To act on violations

EDUCATE

- To address fears
- To change attitudes

ADVOCATE FOR ACTION!

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Supporting text on the sides of the infographic:

- HUMAN RIGHTS FOR ALL
- NOTHING ABOUT US WITHOUT US
- MY BODY MY BUSINESS
- HIV STIGMA IS THE REAL KILLER

How stigma affects the HIV response

UNAIDS and the World Health Organization (WHO) cites fear of stigma and discrimination as the main reason why people are reluctant to get tested, disclose their HIV status and take antiretroviral drugs (ARVs).¹⁶

One study found that participants who reported high levels of stigma were over four times more likely to report poor access to care.¹⁷ This contributes to the expansion of the global HIV epidemic and a higher number of AIDS-related deaths.

An unwillingness to take an HIV test means that more people are diagnosed late, when the virus may have already progressed to AIDS. This makes treatment less effective, increasing the likelihood of transmitting HIV to others, and causing early death.

For example, in the United Kingdom (UK), many people who are diagnosed with HIV are diagnosed at a late stage of infection, defined as a CD4 count under 350 within three months of diagnosis. Although late diagnosis of HIV has declined in the UK in the last decade, from 56% in 2005 to 39% in 2015, this figure remains unacceptably high.¹⁸

In South Africa, stigma stopped many young women involved in a trial on HIV prevention from using vaginal gels and pills that would help them stay HIV free. Many reported being afraid that using these products would lead them to being mistakenly identified as having HIV, and so the fear of the isolation and discrimination that being identified as living with HIV would bring led them to adapt behaviours that put them more at risk of acquiring the virus.¹⁹

The epidemic of fear, stigmatization and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention behaviours, including use of family planning services. ²⁰

In 2015, WHO released new treatment guidelines that reflect the need to address stigma and discrimination as a barrier to accessing HIV treatment.²¹

Forms of HIV stigma and discrimination

HIV and AIDS-related stigma can lead to discrimination, for example, when people living with HIV are prohibited from travelling, using healthcare facilities or seeking employment.

Self-stigma/internalised stigma

Self-stigma, or internalised stigma, has an equally damaging effect on the mental wellbeing of people living with HIV or from key affected populations. This fear of discrimination breaks down confidence to seek help and medical care.²²

Self-stigma and fear of a negative community reaction can hinder efforts to address the HIV epidemic by continuing the wall of silence and shame surrounding the virus. Negative self-judgement resulting in shame, worthlessness and blame represents an important but neglected aspect of living with HIV. Self-stigma affected a person's ability to live positively, limits meaningful self agency, quality of life, adherence to treatment and access to health services.²³

In Zimbabwe, Trócaire and ZNNP+ designed, implemented and evaluated a 12-week pilot programme to support people living with HIV to work through self-stigmatising beliefs. After the 12 weeks, participants reported profound shifts in their lives. The majority of participants (61%) reported a reduction in self-stigma, depression (78%) and fears around disclosure (52%), and increased feelings of satisfaction (52%) and daily activity (70%).²⁴

Evidence suggests people from key affected populations are also disproportionately affected by self-stigma. For example, a study of men in China who have sex with men found that depression experienced by participants due to feelings of self stigma around homosexuality directly affected HIV testing uptake.²⁵

Similarly, a study of men in Tijuana, Mexico who have sex with men found that self-stigma was strongly associated with never having tested for HIV, while testing for HIV was associated with identifying as being homosexual or gay and being more 'out' about having sex with men.²⁶

In countries that are hostile to men who have sex with men and other key populations, innovative strategies are needed to engage individuals in HIV testing and care programmes without exacerbating experiences of stigma and discrimination.

I am afraid of giving my disease to my family members-especially my youngest brother who is so small. It would be so pitiful if he got the disease. I am aware that I have the disease so I do not touch him. I talk with him only. I don't hold him in my arms now.

- woman in Vietnam ²⁷

Governmental stigma

A country's discriminatory laws, rules and policies regarding HIV can alienate and exclude people living with HIV, reinforcing the stigma surrounding HIV and AIDS.

In 2014, 64% of countries reporting to UNAIDS had some form of legislation in place to protect people living with HIV from discrimination.²⁸ While, conversely, 72 countries have HIV-specific laws that prosecute people living with HIV for a range of offences.²⁹

Criminalisation of key affected populations remains widespread with 60% of countries reporting laws, regulations or policies that present obstacles to providing effective HIV prevention, treatment, care and support.³⁰ As of 2016, 73 countries criminalised same sex activity,³¹ and injecting drugs use is widely criminalised, leading to high incarceration levels among people who use drugs.³²

More than 100 countries criminalise sex work or aspects of sex work.³³ Even in countries where sex work is at least partially legal the law rarely protects sex workers and many are at risk of discrimination, abuse and violence from both state and non-state actors such as law enforcement, partners, family members and their clients.³⁴ For example, some 15,000 sex workers in China were detained in so-called custody and education centres in 2013.³⁵

Case study: Ending criminalisation of HIV transmission in Australia

Laws that criminalise HIV non-disclosure, exposure and transmission perpetuate stigma and deter people from HIV testing and puts the responsibility of HIV prevention solely on the partner living with HIV.³⁶

In May 2015, the Australian state of Victoria repealed the country's only HIV-specific law criminalising the intentional transmission of HIV. The repealed law - Section 19A of the Crimes Act 1958 - carried a maximum penalty of 25 years imprisonment, even more than the maximum for manslaughter (which is 20 years).³⁷

The legislation to repeal the law was developed through the collaboration of several stakeholders, including legal, public health and human rights experts and representatives of people living with HIV. It was seen as a major step forward for the rights of people living with HIV.³⁸

Restrictions on entry, travel and stay

As of September 2015, 35 countries have laws that restrict the entry, stay and residence of people living with HIV. In 2015, Lithuania became the most recent country to remove such restrictions.³⁹

As of 2015, 17 countries will deport individuals once their HIV positive status is discovered, five have a complete entry ban on people living with HIV and four require a person to be able to prove they are HIV negative before being granted entry.⁴⁰

Deportation of people living with HIV has potentially life-threatening consequences if they have been taking HIV treatment and are deported to a country that has limited treatment provision. Alternatively, people living with HIV may face deportation to a country where they would be subject to even further discrimination - a practice that could contravene international human rights law.⁴¹

Healthcare stigma

Healthcare professionals can medically assist someone infected or affected by HIV, and also provide life-saving information on how to prevent it.⁴² However, HIV-related discrimination in healthcare remains an issue and is particularly prevalent in some countries. It can take many forms, including mandatory HIV testing without consent or appropriate counselling. Health providers may minimise contact with, or care of, patients living with HIV, delay or deny treatment, demand additional payment for services and isolate people living with HIV from other patients.⁴³

For women living with HIV, denial of sexual and reproductive health and rights services can be devastating. For example, 37.7% of women living with HIV surveyed in 2012 in a six-country study in the Asia-Pacific region reported being subjected to involuntary sterilisation.⁴⁴

Healthcare workers may violate a patient's privacy and confidentiality, including disclosure of a person's HIV status to family members or hospital employees without authorisation.⁴⁵ Studies by WHO in [India](#), Indonesia, the Philippines and [Thailand](#) found that 34% of respondents reported breaches of confidentiality by health workers.⁴⁶

People from key affected populations may face additional discrimination in healthcare settings. Discriminatory attitudes held by health providers may also lead them to make judgements about a person's HIV status, behaviour, sexual orientation or gender identity, leading individuals to be treated without respect or dignity. These views are often fuelled by ignorance about HIV transmission routes among healthcare professionals.⁴⁷

Case study: Reducing stigma and discrimination among healthcare workers in Thailand

In 2012, half of all people living with HIV in Thailand were starting treatment very late and had CD4 counts under 100. HIV stigma was identified as a major barrier to service uptake so health authorities set a target to cut HIV-related stigma and discrimination by 50% by 2016.

⁴⁸

The Ministry of Public Health found that over 80% of healthcare workers had at least one negative attitude to HIV, while roughly 20% knew colleagues who were unwilling to provide services to people living with HIV or provided them substandard services.[49](#)

More than half of respondents reported using unnecessary personal protection measures such as wearing gloves when interacting with people living with HIV. 25% of people living with HIV surveyed said that they avoided seeking healthcare for fear of disclosure or poor treatment, while a third had their status disclosed without their consent.[50](#)

In response to these findings, the Ministry of Public Health, in collaboration with civil society and international partners developed initiatives to sensitise healthcare workers in both clinical and non-clinical settings.[51](#)

Early results in 2014 indicated that improving the attitude of healthcare workers doesn't just improve care for people living with HIV but has wider societal benefits as they are seen as role models.[52](#)

As of 2017, Thailand had collected data from 22 provinces. The Thai Ministry of Public Health is rolling out an accelerated system-wide stigma reduction programme, in collaboration with civil society and concerned communities.[53](#)

A study of health providers in urban health facilities in India found 55-80% of providers displayed a willingness to prohibit women living with HIV from having children, endorsed mandatory testing for female sex workers (94-97%) and stated that people who acquired HIV through sex or drugs "got what they deserved" (50-83%).[54](#)

These experiences may leave people living with HIV and people from key affected populations too afraid to seek out healthcare services, or be prevented from accessing them – for instance, if a nurse refuses to treat a sex worker after finding out about their occupation. It also prevents many people from key affected populations being honest with healthcare workers if they're a sex worker, have same-sex relations, or inject drugs, meaning they are less likely to get services that could help them.[55](#)

When I visited a VCT [voluntary counseling and testing] clinic, health personnel were not polite and immediately asked me if I was a sex worker. A doctor asked me outright, 'Are you HIV positive?' This discouraged me from going to the clinics.

- *Payal, 18, Nepal* [56](#)

Employment stigma

In the workplace, people living with HIV may suffer stigma from their co-workers and employers, such as social isolation and ridicule, or experience discriminatory practices, such as termination or refusal of employment.[57](#)

Evidence from the People Living with HIV Stigma Index suggests that, in many countries, HIV-related stigma and discrimination are as frequently or more frequently a cause of unemployment or a denial of work opportunity as ill health.[58](#)

Key findings from people living with HIV in nine countries across four regions in 2012 found that,

as a result of their HIV status, between 8% (Estonia) and 45% (Nigeria) of respondents had lost their job or source of income; between 5% (Mexico) and 27% (Nigeria) were refused the opportunity to work, and between 4% (Estonia) and 28% (Kenya) had the nature of their work changed or had been refused promotion. In addition, 8% of respondents in Estonia to 54% in Malaysia reported discriminatory reactions from employers once they were aware of the employee's HIV status. Similarly, 5% in Estonia to 54% in Malaysia reported discriminatory reactions from co-workers who became aware of their colleague's HIV status.⁵⁹

It is always in the back of your mind, if I get a job, should I tell my employer about my HIV status? There is a fear of how they will react to it. It may cost you your job, it may make you so uncomfortable it changes relationships. Yet you would want to be able to explain about why you are absent, and going to the doctors.

- HIV-positive woman, UK ⁶⁰

By reducing stigma in the workplace (via HIV and AIDS education, offering HIV testing, and contributing towards the cost of ARVs) employees are less likely to take days off work, and be more productive in their jobs. This ensures people living with HIV are able to continue working.⁶¹

Community and household level stigma

Community-level stigma and discrimination towards people living with HIV can force people to leave their home and change their daily activities.

In many contexts, women and girls often fear stigma and rejection from their families, not only because they stand to lose their social place of belonging, but also because they could lose their shelter, their children, and their ability to survive. The isolation that social rejection brings can lead to low self-esteem, [depression](#), and even thoughts or acts of suicide.⁶²

The International Center for Research on Women (ICRW) reports that in Bangladesh more than half of women living with HIV have experienced stigma from a friend or neighbour and one in five feel suicidal. In the Dominican Republic, six out of ten women living with HIV fear being the subject of gossip, while in Ethiopia, more than half of all women living with HIV report having low self-esteem.⁶³

They [my family] were embarrassed and didn't want to talk to me. My mother essentially said, 'Good luck, you're on your own.'

- Shana Cozad from Tulsa, USA, on her family's reaction after she tested positive for HIV.⁶⁴

A survey of married HIV-positive women (15-29 years) in India found 88% of respondents experienced stigma and discrimination from their family and community. Women with older husbands and from household's with lower economic status were significantly more likely to experience stigma and discrimination from their husbands' family as well as from friends and neighbours.⁶⁵

Stigma and discrimination can also take particular forms within community groups such as key

affected populations.

For example, studies have shown that within some lesbian, gay, bisexual, transgender and intersex (LGBTI) communities there is segregation between HIV-positive and HIV-negative people, where people associate predominately with those of the same status.[66](#) [67](#)

Ending HIV stigma and discrimination

The use of specific programmes that emphasise the rights of people living with HIV is a well-documented way of eradicating stigma. As well as being made aware of their rights, people living with HIV can be empowered in order to take action if these rights are violated.[68](#)

Ultimately, adopting a human rights approach to HIV and AIDS is in the public's interest. Stigma blocks access to HIV testing and treatment services, making onwards transmission more likely. The removal of barriers to these services is key to ending the global HIV epidemic.[69](#)

In March 2016, UNAIDS and WHO's Global Health Workforce Alliance launched the Agenda for Zero Discrimination in Healthcare. This works towards a world where everyone, everywhere, is able to receive the healthcare they need with no discrimination, in line with The UN Political Declaration on Ending AIDS.[70](#) Zero discrimination is also at the heart of the UNAIDS vision, and one of the targets of its Fast-Track response. This focuses on addressing discrimination in healthcare, workplace and education settings.[71](#)

As part of this work:

- A virtual community of practice, Equal Health for All, has been created to facilitate the sharing of communication, collaboration and experiences in implementing the action plan. Over the year, its membership grew to more than 160 members from more than 70 organisations.[72](#)
- In Malawi, the National Association of People Living With and Affected by AIDS, in partnership with Airtel Malawi and UNAIDS, is using an SMS-based reporting system to provide real-time monitoring of experiences of stigma and discrimination faced by people living with HIV in the healthcare sector.[73](#)
- In Argentina, 21 service centres friendly to LGBTI people aim to increase the accessibility and acceptability of health services for key affected populations. Healthcare professionals have been trained on the specific healthcare needs of LGBTI people as well as on non-discrimination, accessible opening hours, and the active involvement of LGBTI people in the design and functioning of services.[74](#)
- In 2016, Kenya reaffirmed its commitment to end HIV-related stigma and discrimination by embarking on a national 'Kick out HIV stigma' campaign. This aims to leverage the power of football to mobilise young people to end HIV stigma and link them to stigma-free HIV testing, treatment and care.[75](#)

Case study: Strengthening the rights of people living with HIV in Ghana

Although Ghana's Constitution protects all citizens from discrimination in employment, education and housing and ensures their right to privacy, there is ambiguity in the way these provisions apply to people living with HIV and to key affected populations.[76](#)

The Patients' Charter protects people living with HIV from discrimination within the healthcare system, but they are difficult to enforce outside of public health facilities. In addition, consensual sex between adult males and sex work is criminalised, deterring sex workers and men who have sex with men from seeking healthcare services.[77](#)

To overcome these obstacles, a web-based reporting mechanism was launched in December 2013. People living with HIV can directly report to the Commission by SMS or through the reporting system's website, and they can choose to remain anonymous. This triggers an

investigation involving human rights organisations and lawyers.⁷⁸

By September 2015, 32 cases of discrimination had been recorded, and 13 of them have been resolved. Complaints have included violence, blackmail and denial of employment, healthcare and education.⁷⁹

However, a study of the implementation of the Charter at a sample of clinics found that, while healthcare staff were aware of the existence of the patients' Charter and also knew some of its contents, the majority of patients had no knowledge of either the existence or the contents of the Charter and were therefore unable to utilise it to tackle experiences of stigma and discrimination in healthcare settings.⁸⁰

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