

Challenging HIV stigma together



People living with HIV and healthcare workers* share perspectives on HIV-related stigma to create change

*Healthcare workers refers to anyone involved in the care of people living with HIV, including doctors, nurses, pharmacists, and other professionals, as well as community health workers

[Click here for the healthcare workers' perspective](#)

Challenging HIV stigma together

Healthcare workers may not realize the potential for stigma and how it affects people living with HIV, or mistakenly believe that these issues are in the past



Speaking up does not mean challenging your doctor, but working together to meet your clinical and non-clinical goals

Everyone deserves to be treated equally and with kindness, no matter their HIV status



By recognising possible sources of HIV-related stigma in healthcare settings, and addressing stigma together, healthcare workers can:



Help individuals live a rich and full life



Improve mental health and clinical outcomes



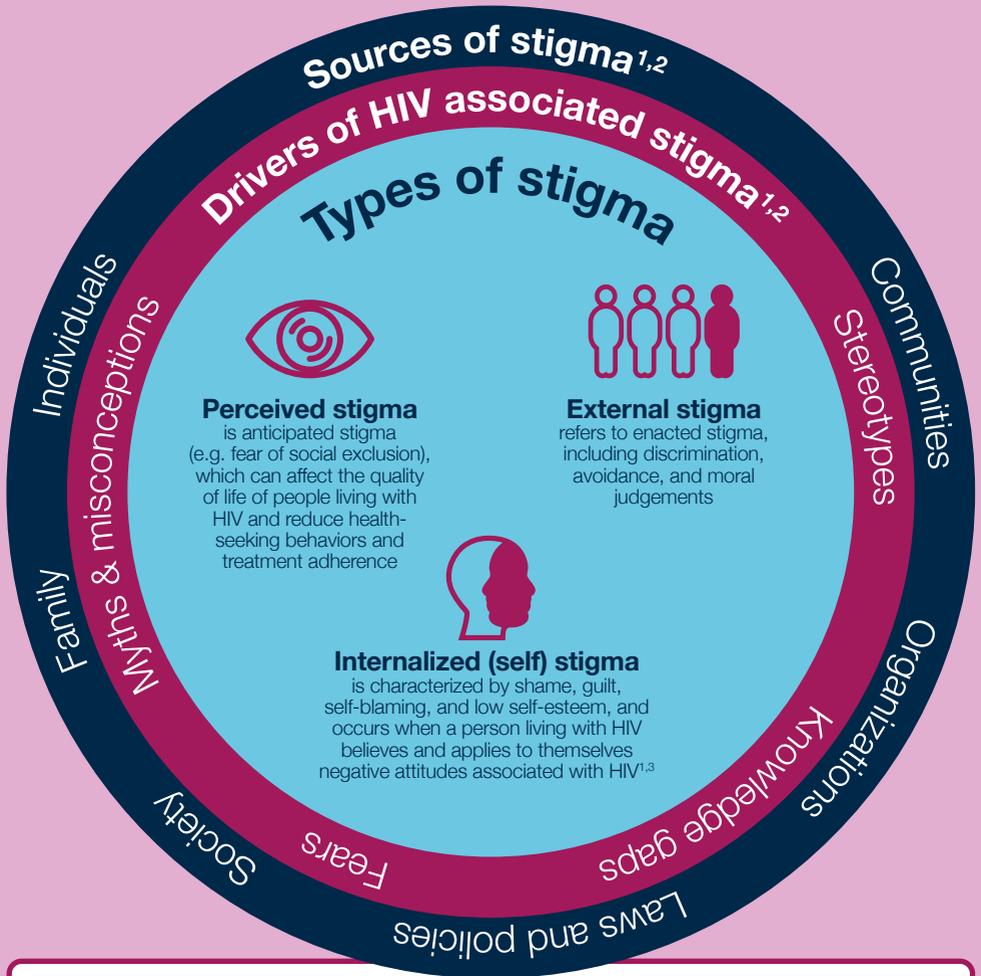
Prevent HIV-related complications and transmission

Challenging HIV stigma together

[Click here for the perspective of people living with HIV](#)

What is stigma?

Stigma associated with HIV is broad, dynamic, and multidimensional¹



People living with HIV may experience multiple and intersecting stigmas related to:^{2,3}

- Age
- Gender
- Sexuality
- Race/ethnicity
- Drug use
- Sex work
- Migration status

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Understanding healthcare workers' behavior

Healthcare workers may be unaware of how their actions or the clinic's policies could be inadvertently stigmatizing to people living with HIV¹



Short appointments (and, increasingly, virtual appointments) mean healthcare workers tend to focus on aspects like viral load and medications rather than mental health and wellbeing

For clinicians, an undetectable viral load is key for reducing the risk of complications and halting any possible further transmission of HIV



"I don't think lack of attention to mental health and wellbeing happens because doctors don't want to explore it, I think it's because they haven't got the time... and often don't know the best way to explore it"



Healthcare workers may not feel confident or comfortable discussing stigma or psychological issues, or not know how to start the conversation. They may struggle to balance being friendly with being clear and professional



Having limited knowledge of HIV, and limited experience providing care to people living with HIV, means non-specialist healthcare workers might not be up-to-date on HIV transmission, treatments, and initiatives



Key fact: transmission of bloodborne pathogens through occupational blood exposure is extremely low in the real world^{2,3}



Some policies or practices that lead to stigma may have become institutionalized over time, such as prominent labels on the medical records of people with HIV



"There's scheduling of surgical or dental procedures to always be the last case of the day... it's not because they are really afraid of transmission, but they have been doing it for 20 years and just haven't questioned it. Providers think that it increases convenience for clients... but from the client's perspective, it can be very stigmatizing"



Precautions may be taken to manage the risk of exposure to HIV from people who are undiagnosed or not on treatment, rather than to explicitly target all people living with HIV



In some countries, healthcare workers may also experience stigma for working with people living with HIV or with LGBTQ, or sex worker populations generally

HIV-related stigma within a healthcare setting can lead to low levels of testing, delayed diagnosis, low uptake of PrEP/PEP, poor treatment adherence, and avoidance of healthcare and support services



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LGBTQ, lesbian, gay, bisexual, transgender and queer
PEP, post-exposure prophylaxis PrEP, pre-exposure prophylaxis

What can healthcare workers do to address HIV-related stigma?



Use open, non-judgemental language

Healthcare workers have a responsibility to choose their words carefully



Enquire about a client's experience of stigma, reassure them you are available to talk, and encourage them to ask for help



Be aware of, and refer clients to, other support services

(e.g. counselor, psychiatrist, peer support)



Employ responsible and appropriate questioning

Are you engaged in care? Are you on treatment?
Are you undetectable?



Use tools to facilitate discussion, prioritization, and management of issues

(e.g. distress thermometer)



Involve people living with HIV in conversations about treatment priorities and all decisions about their care

Healthcare workers have a responsibility to keep up-to-date with advances in HIV



Reach out to an experienced colleague or specialist for advice



Adopt a multidisciplinary team approach to managing HIV



Train everyone (including front-line and reception staff) to provide a stigma-free service that protects the privacy of people living with HIV



Elicit feedback about client's experience at their clinic



Consider how community-led services might be integrated to improve HIV testing and PrEP/PEP uptake in communities

Unequivocally communicate that

U=U¹

undetectable untransmittable

means people living with HIV can live a rich and full life

It is well-established that people treated for HIV who have an undetectable viral load cannot pass on the infection

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[Click here for the perspective of people living with HIV](#)

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1. Prevention access campaign. Undetectable=Untransmittable. <https://www.preventionaccess.org/undetectable>. Published July 2016. Accessed September 2021.

Stigma can be a barrier to accessing care for people living with HIV

HIV-related stigma can have a major impact on health-seeking behavior, particularly in some countries where people living with HIV experience high levels of discrimination from family, community members, and healthcare workers.¹ Such fear of stigma and a lack of knowledge about HIV contribute to:



Low rates of testing¹



Poor engagement with health services and low participation in HIV-related activities (e.g. education sessions)¹



HIV-related stigma can be compounded in some countries by a fear of prosecution for transmitting HIV or for associating with LGBTQ populations



Feeling better on treatment, fear of disclosing status, and financial worries can lead people to not follow through with treatment²



Attempts to hide their appearance when accessing care, to avoid being recognized and 'outed' as HIV-positive¹

"Everyone knows you have HIV... walking into the HIV clinic to get your medications is already challenging. It would be cheaper and more private if medications were sent by mail, and you don't have to face the stigma" – Indonesia

Being diagnosed with HIV can trigger feelings of isolation, shame and guilt, suicidal thoughts, and fear of others' reactions or judgement



"There's still that element of stigmatization because of how you obtain it" – UK

"I only disclosed about 10 years ago... because I had 2 younger children and so I didn't want any complications at school with their friends... so I tried to keep it secret" – Italy

"A friend died of AIDS 2 years ago in a rural community because he was too afraid to tell anybody. He refused to take his ARV treatment... even though he could have it delivered to his home, he was worried that his neighbors would find his medication" – UK

"The first thing they (doctors, peer support) tell you is 'don't let anyone know about your status, because you'll be isolated for that'" – Indonesia

"I have felt that many of the things that other people are not denied, we are denied" – Italy

"I had to ask the children's doctor... to call the school and tell them that my children don't have HIV" – The Netherlands

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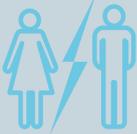
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LGBTQ, lesbian, gay, bisexual, transgender and queer

People living with HIV can experience a range of stigmatizing behavior in the healthcare system



Please note that these perspectives are from people living with HIV in different countries around the world, and some are from many years ago.



Healthcare workers avoiding physical contact, mistakenly fearing transmission of HIV

"The doctors didn't want to touch me at all" – Indonesia

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Difficulty accessing treatment

"It's difficult to find a dentist that will take care of you...
"... you have to struggle to get even minor interventions in healthcare settings" – Italy

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Stigmatizing language or practices

"You get there early [for gastroscopy], [but] you're the last one who is examined. When you ask why... [they say] 'We don't have the right equipment to sterilize everything'... It is an awful moment" – Italy

"Why didn't you say from the beginning of your visit that you have HIV? Now we have to disinfect the whole gynecology office!" – Romania



Healthcare workers asking about how HIV was contracted, for no obvious medical reason

"I had cancer... my doctor asked me questions like 'How did you get HIV?', which really shouldn't matter – UK

"When my GP said 'How did you get that?', rather than seeing me as someone who wasn't well... his first reaction was to get answers for himself" – Ireland

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Healthcare workers taking extra, unnecessary precautions

"I ended up in the emergency room, and one member of staff there triple-gloved because... I've got HIV" – UK

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Discouraging having children

"Absolutely not, you're not allowed to have children, you are going to die. You'd better buy your own coffin" – Burundi



Personal values and religious beliefs can lead healthcare workers to make assumptions and judgements about morality

"Healthcare workers need to leave these biases and religion out of their work but, unfortunately, that's just not what happens a lot of the time" – Ireland

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Disclosure without consent

"I experienced having my status disclosed to family members that I hadn't told about my HIV yet, which was quite a traumatic event... just awful, really" – UK

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A different postnatal experience

"Some women say they are given the baby at arm's length... that tenderness and kindness isn't there" – UK

Overcoming stigma as a person living with HIV

Discrimination, avoidance, and moral judgements from others can affect people at their most vulnerable

People living with HIV have used these strategies to help challenge stigma and secure their rights



Self-reflection, involving understanding personal beliefs, thoughts, and feelings about HIV, can help people recognize perceived and enacted stigma, while also improving self-esteem and wellbeing¹

“Eventually you realize it’s just another condition, and it takes a while” – UK

“Many people with HIV have had to become ‘expert clients’. We’re really used to getting quite involved and talking about our care. Very often I find I know more about HIV than my GP” – UK



More information can help people living with HIV feel equipped to manage stigma² and encourage them to take an active role in healthcare decisions



Seek help through counseling and care services, which provide a safe and confidential space to talk and receive support.^{2,3} Peer groups or networks are also a valuable source of support, guidance, and education^{2,4}



Speak up if you witness or experience stigmatization

“When you see that you are being stigmatized, don’t let it go. Correct them immediately. Tell them, because nobody else is going to do it for us. We have to save ourselves” – The Netherlands

“We are people, and we deserve to have equal rights, equal health, to be treated equally, as anyone who’s not living with HIV” – Burundi



Understand your rights to healthcare and privacy³

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[Click here for the healthcare workers’ perspective](#)

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