

# Risk communications and community engagement public health advice on understanding, preventing and addressing stigma and discrimination related to monkeypox

1 September 2022

This public health advice from PAHO/WHO provides information on the potential impact of stigma, recommended language and actions to counter stigmatizing attitudes and discriminatory behaviours and policies related to the monkeypox outbreak. It will be updated as more is known about effective strategies against stigma and discrimination in the context of this outbreak.

## Overview



An outbreak of monkeypox, a viral infectious disease, is currently being reported in countries where the disease had not been found before. The risk of monkeypox is not limited to any one community or any one place. Anyone who has close contact with someone with monkeypox is at risk.

The outbreak of monkeypox in newly affected countries has mostly been identified in gay, bisexual people and other men who have sex with men who have had recent sexual contact with a new partner or partners. Communities of trans and gender diverse people linked to the same sexual networks have also been affected.

While the risk is not limited to these groups, the evolution of this outbreak has been significantly concentrated. As a result, there has been an increase in stigma and discrimination against men who have sex with men, trans people and broader lesbian, gay, bisexual, trans, queer and intersex communities and their families. Similarly, the stigma, discrimination, criminalization, xenophobia and racism towards communities from previously affected regions has increased as a result of the outbreak of monkeypox.

**Stigma and discrimination connected to any disease, including monkeypox, are never acceptable. They can have a serious impact on health outcomes and undermine the outbreak response by making people reluctant to come forward or seek care. This increases the risk of transmission – both within the most affected communities and beyond.**

**The impact of stigma and discrimination on the monkeypox outbreak must be mitigated through strategies oriented to promote access to health services and support, creating an enabling environment in which they are able to communicate their symptoms.**

## A note before we start



*People often stigmatize others without being aware that they're doing it, and without any malicious intent. People automatically make judgments about others without realizing how*

*it might affect them. In fact, most people have felt ostracized or been treated like a minority*

*at some time in their lives. We all find ourselves perpetuating harmful stereotypes or falling back on unconscious biases at times. Being aware of one's own unconscious bias is important, but even more important is to not allow those implicit biases to cause discrimination to be enabled or ignored.*

*Proactively reflecting and acting on our own language, behaviour and intentions as individuals and as agencies is essential to reducing the harm caused by stigma and discrimination. Having good intentions is not enough – this interim guidance is for everyone working on or concerned by monkeypox. Fear of perpetuating stigma and discrimination should not stop individuals and organizations from speaking up on important issues; the most important thing we can do is to be reflective, seek feedback, call out stigma and discrimination where we see it and be open to learning and changing our behaviour.*

## Target audiences



Governments, UN agencies, civil-society organizations, non-governmental organizations, health workers, community leaders and the media working on monkeypox.

## What are stigma and discrimination?



Stigma in the context of health is the negative association between a person or group of people who share certain behaviours and a specific disease. Stigma is often fueled by fear or anxiety, but stigmatizing language can also be used by people accidentally with no bad intentions due to a lack of awareness. Discrimination is the behaviours that result from stigmatizing attitudes or beliefs.

People who are stigmatized may be rejected, stereotyped, discriminated against, abused and/or experience violence directed at them because of a perceived or real link with the disease. Stigma - or fear of stigma - negatively affects those with the disease. People who don't have the disease but share other characteristics with those who do may also experience stigma. Some people, including families or friends, may be stigmatized by their association with a group or community that is stigmatized. Health workers may also face discrimination or stigmatizing attitudes for their work with affected populations.

People who have been systemically and historically marginalized may experience a disproportionately higher amount of stigma than the majority population. Stigma can be associated with historical and religious attitudes and perceptions toward certain groups.

Layered or intersectional stigma occurs when a group that is already marginalized for one reason is additionally marginalized when they are identified with a different stigmatized group or factor. For example, someone who uses drugs or alcohol in a harmful way may be stigmatized for their substance use and further stigmatized if they are perceived by others as having a connection to other health issues.

## What do stigma and discrimination look like?



Stigma can take many forms, including:

- Stereotyping
- Negative attitudes
- Hostility
- Judgement
- Perceptions that the individual(s) 'cause' or 'deserve' bad things
- Negative portrayals in popular culture, the media or public discourse

Examples of discrimination include:

- Policies, services and opportunities that exclude or miss certain people
- Isolating some groups of people from others
- Hostile behaviour
- Hate speech
- Using harmful, mocking or derogatory language
- Harassment
- Violence
- Bullying

## Stigma and discrimination in the current outbreak of monkeypox

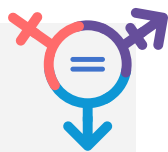


The current monkeypox outbreak has provoked stigma and discriminatory behaviours and language against people from countries where monkeypox has been found in the past in West and Central Africa, and against gay, bisexual and other men who have sex with men and trans and gender diverse people in all regions, as well as against others who have or who are perceived to have been in contact with someone who has contracted monkeypox.

Stigma associated with monkeypox may be associated with the following factors:

- Monkeypox is being found in new places and possibly spreading in new ways. There are still many unknowns, which fuels fear. Fear of the unknown often increases feelings of anxiety and may fuel a desire to assign blame or responsibility to others.
- Many people have existing unconscious biases around race and sexual behaviour which can unintentionally fuel stigma and discrimination.
- Some people with important contributions to addressing monkeypox, including health workers, may avoid engaging for fear of association with the disease and those most impacted.
- Monkeypox offers further opportunities for those already focused on hate, racism and homophobia. Some communities may already be subject to racism, societal perceptions and judgmental attitudes about sexual orientation and gender norms.
- The monkeypox outbreak is occurring while the world is still coming to terms with the impact of the COVID-19 pandemic and associated responses. It is understandable that people feel confusion, anxiety, and fear about a disease, especially if they are learning about it for the first time, but it is important not to let fear fuel harmful stereotypes.

## Gender, language and health



Gender norms, roles and relations, and gender inequality and inequity, affect people's health all around the world. Gender-related barriers to healthcare are a reality experienced by many in LGBTQI+ communities. That is why awareness of and considered use of community-appropriate language is crucial.

## Approaches for understanding, preventing and addressing stigma and discrimination

While stigma may not be able to be "fixed" overnight, organizations, communities and individuals can help to push back and address stigma, given a safe environment to do so.

The approaches listed propose key strategies and approaches that can be used to understand, prevent and address stigma and discrimination in different contexts. The most impactful approaches will always be driven by the context, actors, those affected, and other local factors. Consulting with affected communities should be prioritized in all contexts to identify best practices and key challenges.

## Review your own attitudes, behaviours, organizations and policies for unconscious bias, stigma and discrimination



Avoid the assumption that your positive intentions make you exempt from perpetrating stigma and discrimination. Examine your individual or organizational approach to monkeypox to identify any of the issues above. Ask for feedback from affected populations. Ensure that any documents, strategies or plans take a proactive approach to tackling stigma and discrimination and ensuring equitable programmes for those most at risk. Within organizations, drawing on existing documents outlining the consequences for stigma, discrimination, harassment and other forms of negative behaviour can be helpful. Given that many forms of stigma are unconscious or unintentional, it can be helpful to create an environment in which people are willing and able to examine and change their own unconscious biases without fear of judgment, and to learn from mistakes.

## Listen to the needs of those affected



What is experienced as stigmatizing and discriminatory can vary between people and between and even within communities. Affected communities should be consulted to understand

what they are experiencing. Establishing or drawing on existing feedback systems, monitoring online and offline discourse and holding community dialogues can be ways to gather data to inform activities.

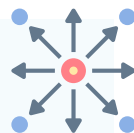
## Draw on empathy



Empathy is the ability to understand and share other people's feelings. Using empathy can help people to understand how painful it is to be stigmatized, discriminated or rejected.

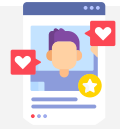
How we communicate about monkeypox is critical in supporting people to take effective action to help combat the disease and to avoid fueling fear and stigma. An environment needs to be created in which the disease and its impact can be discussed and addressed openly, honestly and effectively. Remember empathy rather than sympathy helps ensure the dignity of people affected by monkeypox. Empathetic communication places more emphasis on listening than talking, demonstrating understanding, and acknowledging the hardships that people are facing.

## Spread the facts



Stigma can be heightened by a lack of understanding about how monkeypox is transmitted and treated, and how to prevent infection. Share clear, simple, transparent and accurate country and community-specific information about the outbreak, treatment options, vaccination and where to access healthcare and information.

## Engage social influencers



Leading trusted voices can inform people about monkeypox and help increase awareness of the dangers of stigma. Influencers can urge people to recognize and avoid stigma and amplify messages that reduce discrimination and judgment. Influencers who are asked to communicate information about monkeypox (or any other disease) must be personally engaged, and geographically and culturally aligned with the audiences they seek to influence. Due diligence should be carried out before engaging with influencers to ensure that they will not contribute towards stigma of any group of people.

## Amplify voices, stories and images of people who have experienced monkeypox, stigma or discrimination



First-person stories and images help others relate to unfamiliar situations and circumstances. This can help humanize people affected by the disease and reassure them that most people who contract monkeypox recover fully on their own. It can also help to share stories of the negative impact of stigma and discrimination, and what people have done to address them. contribute towards stigma of any group of people.

## Portray diverse people



Anyone can contract monkeypox. Make sure you portray the range of different people who may be affected by the disease. All materials should show diverse people (e.g., race, gender expression, age) being the most impacted and working together to prevent the spread of monkeypox.

## Support ethical journalism

Words used in media are especially important, as they are likely to shape the popular language and communication on monkeypox. Negative reporting has the potential to influence the perception and treatment of people who have been affected or are suspected to have monkeypox and their families and affected communities.

- Ensure that media outlets are provided with accurate information and guidance about monkeypox and encouraged to integrate nonjudgmental language into their reporting.
- Be aware that journalistic reporting which overly focuses on individual behavior or assigns blame may increase stigma towards people who may have the disease or who may be part of a community that is incorrectly blamed or perceived as being responsible for its spread.

## Considerations for different operational actors, partners and stakeholders

### Health systems and health workers

Health facilities are often the first point of care for people with symptoms that could be monkeypox. It is important to ensure that health workers understand and use appropriate terminology and language to ensure that people feel comfortable and respected while accessing care. This includes making healthcare facilities welcoming places, where people can trust that their privacy and confidentiality will be respected.

People seeking care at health facilities for any reason should be treated with kindness, confidentiality and respect by health workers and other support in health facilities staff alike.



Stigmatizing attitudes (such as vocal or implied disapproval of identities or behaviours) and discriminatory treatment (such as refusing to treat people; testing or treating them without their consent and/or sharing unauthorized personal data) undermines trust and increases the likelihood that people will avoid seeking care.

Discrimination can arise unintentionally through the way in which health systems and processes are designed and delivered. Understanding and addressing the needs and concerns of all staff working in health facilities is key to enabling the health workforce to deliver efficient, personcentered care.

This includes all health workers being aware of their own unconscious biases and judgments too, and adjusting their day-to-day actions to minimize unintentional discrimination during interactions with patients. For example, delaying or avoiding attending to the needs of certain population groups, or wearing excessive PPE in situations not requiring it are subtle reminders that we may be stigmatizing people without realizing it.

Health workers have an important role to play speaking out in their communities to raise awareness and address stigma. Ensure that health workers are properly supported and trained to recognize stigma and have the support structures needed to take steps that can address and avoid it.

Training in interpersonal communication and the importance of avoiding stigmatizing language and discriminatory behaviours should be implemented in health facilities with all staff. Appropriate policies should be in place to deal with discriminatory behaviours. Feedback systems can be established to provide people with opportunities to report stigma and discrimination in health facilities, with measures in place to ensure action is taken and feedback is provided.



## The media



Journalists and others working in the media can play an important role to reduce stigma and discrimination by using appropriate language and images in their work and fact checking their content and reporting before it is disseminated to the public. Organizations working with the media can hold events and information sessions to discuss modes of communicating around this outbreak to reduce the risk of stigmatizing language being used.

## Contact tracing



Stigma and discrimination can have a negative impact on people's interest to report symptoms and share information about their contacts. People may not want to be associated with the idea of possible sexual transmission, or they may not wish to disclose their sexual orientation or sexual histories. People who conduct contact tracing should ensure that confidentiality is respected and privacy measures are in place. For example, ensure that interviews with people seeking care take place in a setting where others cannot overhear what's being said.

Likewise, people who conduct contact tracing should avoid asking patients to elaborate on the specific nature of their contacts' possible exposures. Stigma or fear of stigma may make people reluctant to disclose contacts, which can further hinder efforts to slow the spread of disease.

Contact tracers should encourage people to privately notify their contacts and sexual partners and encourage them to reach out to public health authorities directly for testing and/or care.

## Using non-stigmatizing language in all areas of the outbreak response

The language we use matters in all parts of the outbreak response, not just in communication and community engagement activities.

**When talking about monkeypox, certain words and language may have a negative meaning or connotation and may fuel stigmatizing attitudes. Below are some do's and don'ts on language when talking about monkeypox:**

- » Do talk explicitly about monkeypox or the monkeypox virus and communities most affected.
  - » Don't attach labels of particular demographics to the disease. For example, monkeypox is not a 'gay' disease. Take care to note that anyone in contact with the virus can become infected.
- 
- » Do talk about 'people who have (and/or have had) monkeypox.'
  - » Don't talk about monkeypox cases.
- 
- » Do ask how people are feeling if they tell you they have monkeypox.
  - » Don't ask them how they think they might have been exposed.
- 
- » Do talk about the behaviors that can lead to acquiring or contracting monkeypox.
  - » Don't talk about people spreading monkeypox or infecting others, as it implies that someone is doing this intentionally.

- » Do use language like ‘responding to’ when talking about what is being done to stop the monkeypox outbreak.
- » Don’t use combative language like ‘fighting’ monkeypox.

- » Do speak accurately about the risk, based upon the latest science and health advice.
- » Don’t repeat or share rumors or misinformation.

- » Do talk positively, emphasizing the fact that most people will recover on their own, and the effectiveness of prevention and treatment measures.
- » Don’t overemphasize or dwell on the negative or the threat.
- » Don’t use hyperbolic language or language that generates fear.

- » Take special care when choosing photos or developing graphics to show monkeypox symptoms. Protect people’s privacy and right to anonymity.
- » Don’t use images that can identify individuals or use images without personal consent.

**When talking about the gay and bisexual men and other men who have sex with men, sexual orientation and gender identities:**

- » Do focus on patterns we are currently seeing in the data, for example, ‘Many of the cases we are currently seeing are in communities of men who have sex with men’.
- » Don’t imply that those who identify as gay or bisexual are inherently more at risk, or apply moral judgements or assumptions about people’s sex lives.

- » Do emphasize that everyone who has close contact with someone who is infectious is at risk of becoming infected with monkeypox.
- » Don’t imply that only men who have sex with men are the only ones at risk of contracting monkeypox.

- » Do use the term ‘sexual orientation and gender identity’ when talking about the sex or gender of the person or people are attracted to.

- » Don’t use the term ‘sexual preference.’ Sexual orientation refers to a person’s physical, romantic and/or emotional attraction towards other people. It is comprised of three elements: sexual attraction, sexual behavior, and sexual identity (WHO, 2016).

- » Do use ‘gay, bisexual and other men who have sex with men’ when talking directly to these groups, and ‘men who have sex with men’ when talking more generally.
- » Don’t use acronyms like MSM when speaking as this can be perceived as lazy and dehumanizing – talk about men who have sex with men. MSM can be used in written documents once it has been mentioned in full.

**When talking about monkeypox in West and Central Africa:**

- » Do talk about previously affected and newly affected countries.
- » Don’t talk about endemic and non-endemic countries.

- » Do use pictures of monkeypox symptoms on diverse array of skin colors and seek out pictures from the current outbreak.
- » Don’t rely on old pictures of people from West and Central Africa who have monkeypox when referring to countries from other parts of the world.