

# Stigma in the balance: Ensuring the roll-out of ART decreases stigma

## Stigma and its effects

HIV is highly stigmatised in many settings. Stigma is a major barrier to universal access to HIV prevention, treatment, care and support. It is associated with lower uptake of HIV testing, treatment and prevention services. It can lead to denial of risk and lower likelihood of people adopting preventive behaviours. It discourages people from disclosing their status, which has an impact on uptake of treatment and prevention services.

It was widely assumed that the increasing availability of ART would lead to a reduction of stigma, as it would transform HIV from a “*death sentence*” to a chronic manageable condition and would lead to less dependency and a higher productivity of people living with HIV. It was also predicted to lead to an increase in uptake of HIV testing as the disease would be progressively seen as “*any other disease*”. However, there is evidence that stigma persists despite the increasing availability of treatment. This policy brief explores the impact ART availability has had on stigma, and outlines recommendations for ensuring that the roll-out of ART does lead

to reduction in stigma. It draws on findings from qualitative research carried out against the backdrop of a longitudinal cohort study in a semi-rural area of North-Tanzania. Subsequent studies from two other areas of Tanzania, and Zimbabwe, have reported similar results.

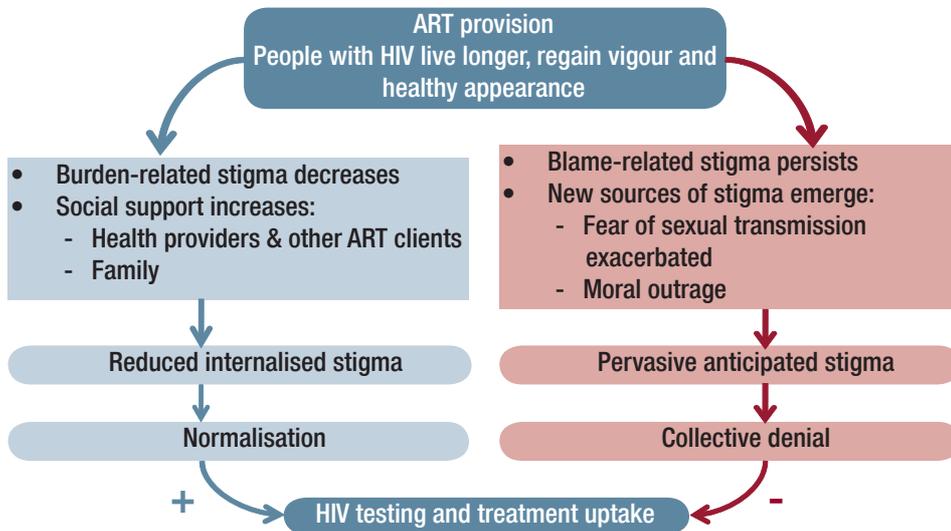
## ART reduces some forms of stigma...

The availability of ART has led to a “normalisation” of HIV. Because ART patients are recovering and able to look after themselves and resume work, burden-related stigma has decreased. “*People see them as normal, they are doing work*”. Self-stigma has also decreased as people living with HIV realise they are not the only ones with HIV, through interaction with health professionals and other people living with HIV at the clinic. Home-based care providers can play a crucial role, sensitising family members to the importance of not stigmatising people living with HIV.

## Key Points

- The Government of Tanzania has done very good work at rolling out ART services to the health centre level and in some areas to dispensary level. However, stigma is threatening successes of the ART program in the country
- HIV-related stigma is still a major problem in Tanzania, preventing people from accessing HIV services (including testing and treatment), and from protecting themselves and others from infection
- The roll-out of ART has led to increasing normalisation of HIV, reducing some types of stigma, but has also led to increases in other types of stigma
- To ensure that ART benefits rural communities in Tanzania, action is needed to promote the normalisation of HIV and prevent a scale-up of stigma

Figure 1: Effect of ART provision on HIV stigma and services uptake



### ...but other types of stigma are not decreasing

HIV is still associated with behaviours that are perceived as degrading and avoidable, and blame-related stigma persists: *“This disease is transmitted through immorality”*. Treatment failure is sometimes attributed to sexual activity and seen to be deserved.

There is also considerable fear-related stigma, as people are concerned that the physical recovery of people with HIV after receiving ART will lead to increased sexual activity and transmission. Because treatment users put on weight and can no longer be visually identified as ill, people are afraid that others will no longer know to avoid having sex with them. Some community members have suggested that people living with HIV should be “marked” so others are aware that they should not have sex with them.

Another source of stigma is “moral outrage”: people who are seen as blameworthy are given economic and nutritional aid through support

programmes in a context where many community members live in extreme poverty.

In addition to these forms of stigma, and because of them, there is often denial of HIV in Tanzania, with illness blamed on witchcraft or “evil forces” rather than HIV.

### Stigma in the balance

Because of these two counter-acting trends, the reduction in stigma and increase in uptake of HIV services has not been as clear as initially predicted. Quantitative work in South Africa even suggests that stigma increased as ART was introduced in the public sector. The scale-up of ART is an important opportunity for tackling stigma but action needs to be taken at both national and local level to strengthen the positive impact of ART on stigma, and reduce the negative effects that have come to light.

### Definitions and types of stigma

**Stigma** is an emotional response to danger that makes people feel safer by blaming ‘others’

**Enacted stigma:** what people do to unfairly disadvantage known or suspected HIV-positive persons

**Anticipated stigma:** The stigma people expect from others if they were known to be HIV positive

**Self-stigma:** Internalised feelings of shame or blame derived from accepting stigmatising judgements of one’s identity

**Secondary stigma:** Stigma which, by association, affects those related to the infected

**Burden stigma:** Stigma derived from the inability of individuals to conduct productive activities and look after themselves

**Fear stigma:** Stigma derived from the fear of being infected by HIV through casual or sexual contact

**Blame stigma:** Stigma derived from the association of HIV with negative behaviours or groups in society, which are blamed for their infection

*Based on: Deacon H. Understanding HIV/AIDS stigma. A theoretical and methodological analysis. HSRC Research Monograph. London: HSRC Press, 2005*

### Increasing visibility and “normalisation”

Increasing the visibility of people living with HIV may help to increase the “normalisation” of HIV, and reduce self-stigma.

- Run periodic sensitisation campaigns that emphasise that HIV can affect anyone, and that testing and treatment is available just like any other disease. A national HIV testing campaign in Tanzania where top government leaders had HIV tests is an example of this.
- Encourage the media to run features on people living with HIV who are willing to disclose their status, after having been counselled on the implications of doing so.
- Encourage the development and communication of anti-stigma public statements by faith organisations.
- Encourage people living with HIV to act as VCT and ART advocates using local traditions in collaboration with formal and informal local leaders.
- Promote VCT uptake of local leaders.

### Training

Training is also important to reduce some of the misconceptions that exacerbate stigma, and encourage key stakeholders to take action against it. This needs to be done at several levels.

- Organise national-level workshops for anti-stigma trainers appointed by Regions / Districts.
- Ensure anti-stigma modules are included in the training provided to local HIV committees.
- Organise workshops addressed to anti-stigma focal points appointed by local HIV committees.

### Reducing fear-related stigma

Reducing fear of people living with HIV is important to reducing stigma.

- Support associations of people living with HIV to develop and share a “chart of rights and responsibilities”
- Promote realistic “positive prevention” strategies
- Consider alternatives to criminalising HIV

### Involving all key stakeholders

Tackling stigma effectively will require cooperation from all key stakeholders.

- Health service providers should participate in local multi-sectoral HIV committees, and share with the committees how HIV is detected and treated.
- Ensure Faith Leaders, people living with HIV and Traditional Healers are part of local HIV committees, and involved in anti-stigma activities.
- Involve home based care providers as family educators about HIV.



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## Recommended Readings

Agnarson AM, Masanja H, Ekstrom AM, Eriksen J, Tomson G, Thorson A. Challenges to ART scale-up in a rural district in Tanzania: stigma and distrust among Tanzanian health care workers, people living with HIV and community members. *Trop Med Int Health*. 2010 Sep 15.

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## Credits

This brief was written by Annabelle South and Maria Roura with the collaboration of Basia Zaba, Jim Todd and Mark Urassa. It draws upon research from the TAZAMA project, funded by the Global Fund to fight Aids, Tuberculosis and Malaria (GFATM), and implemented as a partnership between the Tanzanian National Institute for Medical Research and the London School of Hygiene and Tropical Medicine.

**funded by:**

**DFID** Department for International Development

This document is an output from a project funded by DFID for the benefit of developing countries. The views expressed here are not necessarily those of DFID.



on HIV treatment and care systems

## About Evidence for Action

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, examining issues surrounding HIV treatment and care systems.

The research is organised in four key themes:

1. What "package" of HIV treatment and care services should be provided in different settings?
2. What delivery systems should be used in different contexts?
3. How best should HIV treatment and care be integrated into existing health and social systems?
4. How can new knowledge related to the first three questions be rapidly translated into improved policy and programming?

## Partners:

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