

Technical brief



Quantifying the impact of human rights and gender programmes

Human rights & gender programming

This technical brief explores some of the main challenges in measuring and quantifying the impact of both the human rights context (laws, policies, social norms and practices...) and human rights interventions (human rights-based programmes) on the effectiveness of the HIV response. It focuses mostly on the quantification of the positive impact of human rights and gender programmes and interventions on the response.¹

Difficulties of providing evidence of such impact help explain the relatively low investment in human rights interventions by global and national actors of HIV governance. This is an opportunity for the Alliance to demonstrate its contribution to the human rights-based response to HIV and add to the body of knowledge about quantifying the impact of such a response. The current policy landscape provided by attention to rights, non-discrimination and equality under the new Sustainable Development Goals, and the interest of key HIV actors, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria, on quantifying the impact of human rights interventions is favourable in this regard.

The paper intends to help initiate a broad dialogue across Linking Organisations, Alliance Centres, community-based organisations, Key Population (KP) networks and other partners about how best to capture and articulate the impact of the human rights and gender interventions we carry out and those we are planning. We realise that such a task will need not only to align with, but also to be used in combination with our existing Monitoring and Evaluation (M&E) and data collection systems in a way that can help capture this impact.

In the coming months, we will be exploring this contribution further. We aim to produce technical guidance and standards based on our collective experience to inform our human rights programming and research and our advocacy for the provision of human rights-based responses to HIV globally, regionally and nationally. These areas of work are key pillars of the Alliance's strategy moving towards 2020.

For any comments or suggestions, please contact Enrique Restoy at the Alliance Secretariat. erestoy@aidsalliance.org

About the International HIV/AIDS Alliance

We are an innovative alliance of nationally based, independent, civil society organisations united by our vision of a world without AIDS.

We are committed to joint action, working with communities through local, national and global action on HIV, health and human rights.

Our actions are guided by our values: the lives of all human beings are of equal value, and everyone has the right to access the HIV information and services they need for a healthy life.

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Unless otherwise stated, the appearance of individuals in this publication gives no indication of either sexuality or HIV status.

Introduction: human rights and HIV, an undeniable link

After several decades of responding to the HIV epidemic, few dispute the fact that human rights matter. From the 1990s onwards the global HIV movement was based on a premise that people living with or affected by HIV had the fundamental human right to access treatment, prevention, care and support. Throughout the 2000s and the 2010s there was no declaration or statement on HIV that did not call for an end to the stigma and discrimination of people affected by HIV; not only because they constitute human rights violations, but also because tacking them is a key premise to effectively deal with the epidemic. Well into the 2010s, increasing numbers of experts and policy makers claim that in order to end AIDS, it is imperative to protect and promote the human rights of people affected by HIV.2

On 1st March every year the world celebrates Zero Discrimination Day. This day is testimony to the progress made in acknowledging and addressing HIV-related discrimination in all its forms, from legal to policy to social manifestations. Zero discrimination targets are key in the Joint United Nations Programme on HIV/ AIDS' (UNAIDS) strategy to end AIDS as a major global health crisis by 2030.3 Human rights principles, including non-discrimination and equality are also at the core of the new Sustainable Development Goals.4

Human rights-specific programmes to respond to HIV are now well established among key actors in HIV governance, from UNAIDS to the Global Fund.5 Stigma and discrimination reduction programmes, legal services, monitoring and reforming of laws and practices, sensitisation of law enforcement officers and training of healthcare workers, programmes to tackle gender inequality, harmful gender norms and gender-based violence, and other programmes aimed at eliminating legal barriers to accessing HIV services are fully recognised HIV interventions.6

For the Alliance and ARASA, these programmes should always include core community-led human rights interventions such as responses to individual emergencies, community-led advocacy, and community-owned evidence gathering.7

Are we translating human rights rhetoric about HIV into investment?

Over the past few years, research has made ground-breaking advances, particularly in the use of Antiretrovirals (ARVs) to eliminate the risk of transmission. We might now have the technology to achieve the end of AIDS.8 UNAIDS, the World Health Organization (WHO) and numerous funders of the HIV response have seized the momentum to call for an accelerated response, a fast-track under the 90-90-90 treatment cascade framework, which among other elements, presents a model with several scenarios to end AIDS.9



The assumption might be that, given general consensus about the impact of human rights on the effectiveness of the HIV response, such context and responses would be well integrated into any epidemiological modelling. This would mean that human rights are factored in when determining the various scenarios and foreseen outcomes for the HIV response. They are not. In reality, global HIV governance bodies, donors and governments now recognise the impact that human rights has on the HIV response. Yet when considering the investments required to end AIDS, they thoroughly fail to factor in such impact and the interventions needed to uphold the human rights of affected populations. ¹⁰

As an example, the 90-90-90 strategy presents quantitative data on treatment and adherence in its modelling to end AIDS,¹¹ yet the zero discrimination targets are based on an indicator of a reduction in the number of people reporting discrimination, treated in a disconnected way to the quantitative modelling on which 90-90-90 is based.¹²

As a result of not factoring human rights into the models upon which HIV investments are often decided, human rights-based HIV interventions represent a desperately small proportion of the total HIV funding. It translates into a lack of scrutiny about the real impact of punitive laws and persecutory practices against populations most affected by HIV compared to the thorough analysis of the effectiveness of biomedical interventions. The implications cannot be simply ignored when at least 60 countries have adopted laws that specifically criminalise HIV transmission, and over 78 jurisdictions criminalise same-sex relations.¹³

What is missing in the human rights-HIV relationship? The quantification gap

Two essential immediate considerations need to be exposed. Firstly, all governments must respect, promote and fulfil the human rights of all their citizens without discrimination regardless of whether the violations of their rights have an impact on the HIV response. This is an obligation under international human rights law, enshrined in the constitutions of most countries.¹⁴

Secondly, even putting aside the controversial debate about whether aid should be conditional to human rights guarantees, key stakeholders in the international human rights system, some of which are also key actors in the global response to HIV, should exert their influence over governments which do not uphold the human rights of people affected by HIV.

Strictly from the point of view of HIV investments, a critical problem in promoting human rights-based HIV interventions among donors, governments and HIV governance bodies is the difficulty in measuring and quantifying two types of evidence of human rights impact:

- 1. The direct impact of the human rights context (laws, policies, social norms and practices...) on the effectiveness of the HIV response
- 2. The positive impact of specific human rights and gender programmes on such a response (fig.1).

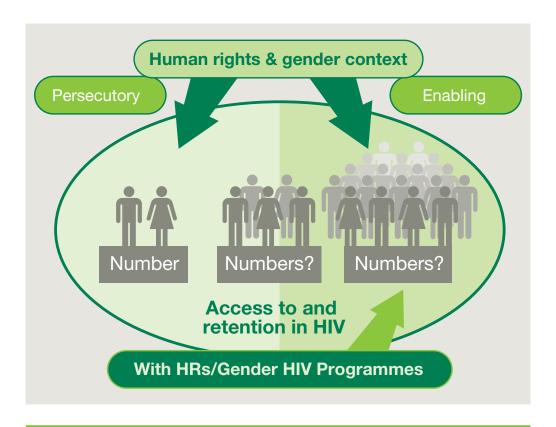


Fig 1

For the first kind of impact, overwhelming evidence shows that laws criminalising same sex practices, sex work, drug use and specific laws to criminalise intentional HIV transmission and non-disclosure and other punitive legislation against populations affected by HIV not only breach the human rights of these populations, they also impact negatively on the effectiveness of the HIV response.¹⁵ Ample evidence shows that law enforcement practices and impunity for violations of the human rights of people affected by HIV draw these populations away from critical HIV prevention, treatment and care and support services, fuelling the HIV epidemic. 16 However, it is hard to quantify such impact on the health outcomes of individuals and communities since very often such impact is not direct, cannot be isolated from a myriad of other structural factors or is felt over a large number of years.

It is arguably harder to quantify the second type of impact, that of human rights and gender interventions on the effectiveness of the HIV response, even though there is a small but growing literature studying the impact of human rightsbased approaches to health on health outcomes.¹⁷

Although human rights-based programmes are established as recognised HIV interventions in global HIV governance, they are often presented as a means to respond to contexts where the human rights of people affected by HIV are abused. An enormous emphasis is often put on the diagnosis of the problem through legal and policy analysis and the identification of such abuses. Today, virtually all national strategic plans on HIV and AIDS (NSPs) incorporate such analyses and all incorporate rhetoric as to the need to base the HIV response on human rights principles. However, very few - if any - analyse and quantify the impacts of specific human rights-based programmes and incorporate such interventions in the budget under national plans; they are not part of the investment frameworks (often Investment Cases) where national responses are developed.¹⁸

This means that, whatever the analysis of the human rights context, HIV investments either work on the assumption that the context does not change, or the assumption that changes in the context occur without the influence of interventions. However, human rights interventions could contribute to either accelerate the creation of a positive context (for example, the passing of laws protecting people living with HIV) or to respond to changes in the context which could impact negatively on the achievement of targets. For instance, many NSPs identify criminalisation of homosexuality as a key barrier to effective HIV services among men who have sex with men (MSM) and transgender people, but they fail to analyse the positive impact of interventions changing this legal framework, or in other words, the opportunity cost of not changing it.

Human rights interventions are also often absent from other important related HIV strategies. Take the example of country concept notes proposed to the Global Fund, which are based on NSPs. Countries submitted 119 concept



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notes to the Global Fund for funding HIV, malaria or TB responses in 2014, but less than 0.1% of the funding requested and granted was for specific human rights interventions, a total of approximately US \$8 million. 19 The difficulty of measuring quantitatively the impact of human rights and gender interventions on the HIV response, in comparison to the ease of measuring the impact of biomedical interventions contributes to the fact that very little funding from HIV donors goes to human rights interventions. UNAIDS estimated in 2015 that the annual global spending for the human rights response to HIV was less than 0.13% of the total AIDS spending in low and middle-income countries.²⁰

What to do to make human rights-based HIV investments happen?

For decades, the human rights system has heavily relied on qualitative approaches to describe human rights contexts based on a system of country reports, reports by UN special rapporteurs and other UN mechanisms. It has also relied on the work of national and international human rights organisations denouncing repressive legal systems, human rights violations and discrimination largely based on personal testimonies. This work is still valid and necessary, and it is still key to capture the depth and nuances of how human rights affect people's lives. Numerous Linking Organisations and partner organisations of the Alliance's have produced human rights reports including evidence from beneficiaries and clients with significant impact.²¹ The Alliance's REAct (Rights, Evidence, Action) Community Based Organisation-owned monitoring and response system is designed to help organisations capture such narrative.²² However, quantification is essential in the world of HIV investments. The challenge both at the macro level of the HIV response and at the micro level of HIV programmes and projects is to find a quantitative framework that helps us analyse the Value For Money (VfM), or rather the Value for People (VfP) of human rights interventions. VFP considers the four 'E's to help ascertain impact: economy, efficiency, effectiveness and equity without undermining the principle that all people are entitled to all human rights.²³

Macro level

At the macro level of the HIV response, the first task for us regarding the quantification of human rights factors and interventions (globally and even nationally) is advocacy. The epidemiological models serving as frameworks for HIV investments by donors and governments at the national level should always consider human rights-related factors. Modelling scenarios should always introduce human rights factors as key variables, for example, scenarios with or without the existence of a particular legislation criminalising populations affected by HIV. Such models should always also quantify the possible positive impacts of specific human rights interventions aimed at addressing the various scenarios.

As with the analysis of any structural interventions, factoring in the human rights and gender context (positive and negative) and the impact of human rights-based interventions even in epidemiological modelling might be difficult, but not impossible. For example, in 2010, the Results for Development Institute estimated that interventions for enhanced legal and policy environments could lower the rate of new HIV infections among adults, then at 2,2 million per year, to 1.3 million per year by 2030.²⁴ More recently, Shannon et al.'s model estimated that decriminalisation of sex work could avert 33-46% of new HIV infections in the next decade through the combined effects of the reduction of violence and police harassment, safer work environments, and fewer HIV transmission pathways.²⁵

Most decision makers accept the enormous influence of the human rights context on the effectiveness of the HIV response. It is inexcusable to fail to systematise the analysis of the impact of human rights in all HIV policies and investment decisions. The new Sustainable Development Goals adopted in 2015 by the United Nations Global Assembly provide a unique framework to quantify the impact of a human rights-based response to the HIV epidemic as they aim to: 'By 2030, end the epidemics of AIDS', and to reduce 'All forms of violence and the promotion and enforcement of non-discriminatory laws and policies'. Both the Global Fund and UNAIDS have expressed their commitment to pursue this agenda.

Micro level

The Alliance can directly contribute to the quantification of the impact of human rights and gender interventions at micro level. In the coming months, we will explore ways to embed analyses in our existing and new programmes, both those which include specific human rights interventions and those which do not but are heavily influenced by the human rights context. In reality, all of our programmes provide human rights-based responses to HIV, starting with the promotion to the right to the highest attainable standard of health. An estimated 80% of beneficiaries of Linking Organisations who are sex workers, Lesbian, Gay, Bisexual, Trans, or Intersex (LGBTI) people, or people who use drugs live in countries where these communities are criminalised and persecuted and their right to health seriously compromised.²⁶

Below are some examples in literature which quantify the impact of human rights on the public health response and the positive impact of human rights programmes; some of them are based on programme implementation data.²⁷ We hope to expand the list below and enrich it in the coming months as we explore further what evidence is available inside and outside the Alliance Linking Organisations:

• Cost analysis is an important tool and some institutions have studied the economic impact of repressive human rights environments, for example, the economic impact of homophobia, often from a macroeconomic point of view. This analysis can also be made at the programme level, for example analysing the rise in unit costs of HIV programmes when they have to respond to a repressive human rights environment (such as through safety and security measures, legal services, and more costly one-to-one outreach activities). This type of analysis is particularly connected with the Alliance's framework analysis of Value for Money (VfM) regarding the criteria of economy and efficiency.²⁸

- Case study approaches are well established methods to measure the impact of human rights interventions including human rights-based approaches to health through a holistic review of secondary sources (laws, policies, programmes and quantitative and qualitative data) supplemented with discussions with health professionals and other informants.²⁹ From an advocacy point of view, this approach permits triangulation of testimonies by people affected and other key informants with analyses of changes in policies and practices such as new legislation initiatives or policy makers' statements,30 and through using specific advocacy M&E tools, such as the Alliance's Measuring Up framework.31
- Respondent level sampling is a common method in public health research. It is based on periodic visits to a set of informants, where changes in health behaviours and outcomes can be registered. It can be expanded to include respondents' experiences concerning human rights issues, for example experiences of discrimination in the public health care settings. When carrying out the study prior to and following a significant human rights-related event (for example the passing of homophobic legislation), the impact of such event on the set of informants can be quantified.³² We are presently planning the combination of such approach with the ongoing implementation of REAct. The AIDS Legal Network (ALN) is using this combined approach to measure the impact of programmes to address gender violence in South Africa and AIDS Alliance India will use it in its Wajood programme with transgender and Hijra organisations in four states.
- Comparison of correlation between human rights factors, for example legislation (either punishing or protecting a particular population affected by HIV) and HIV prevalence/incidence in that population among various countries/states. This analysis is controversial as there are numerous factors contributing to the HIV epidemic (behavioural, communitarian, structural) and the correlation cannot be established only with one of them. However, it is possible when all the other factors are similar across the settings considered.³³
- Most significant change is also a well-established method to assess the impact of programmes, which can also be used when analysing the impact of both changes in the human rights context (deemed either positive or negative) and of specific human rights programmes.34
- Mixed qualitative and medical qualitative analysis combines semistructured interviews with beneficiaries of health programmes (individuals and/or focus groups) with quantitative analyses of HIV status or other health parameters. This allows the comparison of particular human rights experiences among groups identified by a particular health status. For example, Booth et al. in their study among people who use drugs in Odessa found that HIV positive participants were more likely to experience harassment and arbitrary detention by police.³⁵

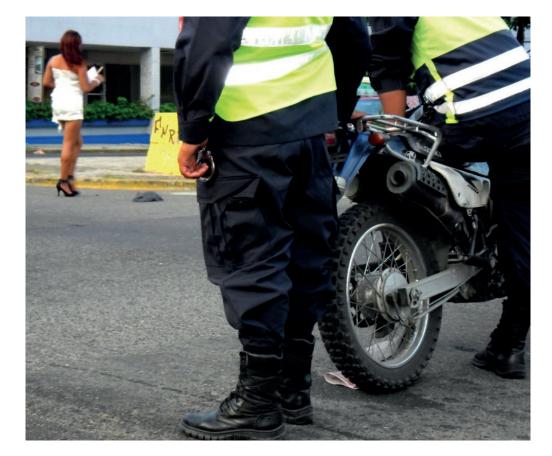
Conclusions and next steps

This paper stresses the need to develop better ways of analysing the quantitative impact of human rights (both the context and interventions) on the HIV response. Without quantification, investments in programmes and interventions to improve the human rights of people affected by HIV as integral to the HIV response are bound to remain low.

This measurement will require a combination of quantitative and qualitative approaches from diverse disciplines that help understand the indirect and longterm impact of human rights on the HIV response and on health in general.

In the coming months, the Alliance will develop its analysis of various existing M&E and data collections systems and methodologies across Linking Organisations and others. We will use, adapt, and apply this to our programmes and in our research to contribute to the growing body of evidence and advocate for human rights and gender interventions to be truly at the core of investments in the HIV response.

We would love to hear your experiences, thoughts and comments about quantifying the impact of human rights on the effectiveness of the HIV response and the positive impact of human rights-based HIV programmes. Please contact Enrique Restoy at the Alliance Secretariat: erestoy@aidsalliance.org



Police controlling a trans* pride parade in San Pedro Sula, Honduras, 2012. © Enrique Restoy and Monica Leonardo.

Endnotes

- 1. This paper refers to gender interventions to encapsulate interventions aimed to reduce gender inequality, harmful gender norms and gender-based violence
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