

# **HIV RESEARCH ON KEY AND VULNERABLE POPULATIONS**

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**Issues in policy and practice  
in eastern and southern Africa**

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**DISCUSSION PAPER**

Nordic Consulting Group



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## **ABBREVIATIONS**

CAB	Community Advisory Board
EHPSA	The Evidence for HIV Prevention in East and Southern Africa
EiA	Evidence into action
ESA	Eastern and southern Africa
HSRC	Human Sciences Research Council
IERC	Institutional Ethics Review Committees
KP	Key populations
KVP	Key and vulnerable populations
LGBTI	Lesbian, Gay, Bisexual, Transgender, Intersex
NCG	Nordic Consulting Group
MSM	Men who have sex with men
NAC	National AIDS Commission
NASCOP	National AIDS and STI Control Programme (Kenya)
NASF	National AIDS Strategic Framework
NSP	National strategic plan
NHRAZ	National Health Research Authority of Zambia
PWID	People who inject drugs
SANAC	South African National AIDS Council
SEP	Stakeholder engagement plan
SW	Sex Workers
TWG	Technical working group

# 1. EXECUTIVE SUMMARY

## 1.1. Introduction

It is increasingly recognised that to reach the global goal of ending the AIDS epidemic by 2030 it will be necessary to strengthen policy and programming for key and vulnerable populations (KVPs) who have been 'left behind'. For these new policies and programmes to be successful, it is critical that they are underpinned by research, and based on evidence. This is particularly important for KVPs who are often stigmatised and marginalised, and the subjects of inaccurate beliefs. Thus, HIV prevention research for KVPs has a fundamental role to play in shaping an expanded national and regional response in sub-Saharan Africa.

This discussion paper looks at the landscape of HIV research for KVPs in eastern and southern Africa (ESA). It examines KVP policy and priorities, the institutional organisation of research, and the contribution of civil society organisations in research. The final section uses the EHPSA programme as a case study for exploring key population engagement in HIV research.

The paper discusses a range of issues relevant to strengthening research for key populations in the region and aims to stimulate discussion on the following questions:

- Is KVP research in practice aligned to KVP policies, research agendas and priorities?
- Are national governments able to lead research for KVPs?
- How can and should KVP organisations be engaged in setting national research agendas and in research practice itself?

The paper focusses on HIV research on adolescents and key populations in the six ESA countries of Kenya, Malawi, South Africa, Swaziland, Tanzania and Zambia.

## 1.2. HIV research agendas and priorities

When discussing HIV research for KPs it is important to understand the context in the six study countries:

- In all six countries key and vulnerable populations are stigmatised and marginalised, especially MSM who face an adverse legal environment in all countries except South Africa.
- The policy context is more favourable than the legal situation would suggest. All six countries have national strategic plans (NSP) that include KPs, though they vary widely in depth and scope.
- Research capacity varies across the six countries. Kenya and South Africa are the only countries with strong academic traditions and research institutions.
- Domestic funding for HIV research is low in all countries, with most research being funded by donor agencies.
- There are six key stakeholder groups involved in HIV research – national government, researchers, donors, multilaterals, implementing partners and KP organisations.

Of the six study countries, only Kenya has a current national HIV research agenda. Three countries are in the process of developing such (South Africa, Zambia, Tanzania), and in two countries (Malawi, Swaziland) the HIV research agenda is part of the broader health research agenda. The lack of clear national priorities and plans for KPs research is an obstacle to rationalising and aligning KP research to national needs.

Technical working groups (TWG) of the national AIDS councils represent appropriate forums for coordinating the six research stakeholders, and for policymaking around KPs. In theory, a TWG is the perfect institution for setting HIV research agendas and for alignment of research with national priorities for adolescents and key populations. Four of the six countries have TWGs for HIV research.

Table 1 in the Annexures on p 16 gives a summary of findings on national policy and research in the six study countries.

### 1.3. Key populations and HIV research

Both KPs and researchers have a strong interest in meaningful engagement and ownership of KPs in HIV research. It is widely recognised that this engagement, at all stages of the research continuum, can improve the quality of research.

KPs may have some influence on the development of national HIV research agendas through their participation in TWGs, and in NSP development, or through advisory groups. They also have a constructive role to play at all stages of the research continuum. These are conceptualisation and design; implementation; data analysis, dissemination and use of research results (evidence into action).

Community Advisory Boards are important modalities of KP engagement in research. A case study of EHPSA's three MSM research programmes and one prisons programme has found that no KP organisations were involved in the conceptualisation and design stage of research. All studies planned to engage KPs in the implementation, data analysis and dissemination phases of the research. There were plans to engage all but the prisoner KPs in research uptake, or evidence-into- action.

### 1.4. Conclusions

- *Alignment of KVP research to KVP policies, research agendas and priorities*  
The prospects for research for key and vulnerable populations to be aligned with national needs, research agendas and priorities are generally weak, but vary across the six countries. **Research priorities are not fully articulated in most countries, and research capacity is weak** in four countries.
- *The ability of national governments to lead research for KVPs*  
**Adverse socio-legal environments**, particularly for key populations, presents a major obstacle for state actors to be proactive in this regard. **The lack of domestic funding for research is another serious obstacle** to national governments' ability to lead HIV research for KPs.
- *The engagement of KP organisations in setting national research agendas*  
KP organisations may contribute to setting national research agendas through their participation in the technical working groups of the national AIDS councils, or through their engagement in formulating national strategic plans. However, in general, **government bodies and donor agencies lead the development of national HIV research agendas and key populations play a limited role.**
- *The engagement of KP organisations in the research process along the research continuum*  
There are mutual benefits, for researchers and KPs, that may be derived from KP engagement throughout the research continuum. Findings from the EHPSA case study suggest that **few, if any, KP organisations are engaged in the conceptualisation and design phases of research.** In the EHPSA research programmes **KP organisations have played a valuable role in implementation and data analysis** and are considered **obvious partners for dissemination and research use.**

The EHPSA programme has pioneered some innovative modalities for KP engagement. These include working closely with KP organisations as research partners, establishing dedicated KP organisations for research participants, and supporting stakeholder engagement plans.

## 2. INTRODUCTION

In line with the global goal of eliminating HIV by 2030, there is a growing emphasis on policy and programming for key and vulnerable populations (KVPs) who have been 'left behind'. For these activities to be successful, it is critical that they are underpinned by research and based on evidence. This is particularly important for KVPs who are often stigmatised, marginalised and the subjects of inaccurate beliefs. Thus, HIV prevention research for KVPs has a fundamental role to play in shaping an expanded national and regional response in sub-Saharan Africa.

The research landscape of the region, however, is not always favourable to providing this essential evidence. Much of the research for HIV prevention is undertaken by international researchers and agencies, who may not be concerned with the alignment of their study topics (or findings) with national needs. Policymakers are much concerned<sup>1</sup> with inequitable relationships between international researchers and those in sub-Saharan Africa and there have been recent calls for low- and middle-income countries to take an active role in leading research, and research collaborations, with researchers from high-income countries<sup>2</sup>.

On the other hand, given the hostile legal environment for most KVPs in the region, national policymakers may not always be best placed to drive the research agenda for stigmatised groups. The solution to this conundrum lies in long-term and intensive collaborations between all relevant national and other stakeholders, including KVPs themselves.

### About this paper

This discussion paper looks at the landscape of HIV research for KVPs in eastern and southern Africa (ESA). It examines KVP policy and priorities, the institutional organisation of research, and the contribution of civil society organisations in research. The final section uses EHPSA as a case study for exploring key population engagement in HIV research.

Research was defined as biomedical research, including basic science, clinical and epidemiological research; socio-behavioural research; and implementation research.

This paper focusses on adolescents, men who have sex with men (MSM), sex workers (SW), prisoners, and people who inject drugs (PWID). There is a particular emphasis on six countries in eastern and southern Africa (ESA) - South Africa, Zambia, Malawi, and Swaziland, Kenya and Tanzania.

The paper discusses a range of issues relevant to strengthening research for key populations in the region and aims to stimulate discussion on the following questions:

- Is KVP research in practice aligned to national KVP policies, research agendas and priorities?
- Are national governments able to lead research for KVPs?
- How can and should KP organisations be engaged in setting national research agendas and in research practice itself?

The paper is based on a longer report, commissioned by EHPSA, researched and written by the Nordic Consulting Group (NCG). An infographic and two EHPSA Shorts are available at: <http://www.ehpsa.org/critical-reviews/hiv-prevention-research>

### Approach

The initial report used data collected through a desk study, literature review, and more than 100 meetings with a range of stakeholders including national AIDS commissions and other government institutions; research institutes; international donor agencies; and civil society actors, including key population-led organisations.

### About EHPSA

The EHPSA programme funds three portfolios of HIV prevention research on adolescents, men who have

1 Much attention was devoted to this topic at the EHPSA Symposium of 2015. See <http://www.ehpsa.org/evidence-into-action/ehpsa-events/symposium-june-2015>

2 Chu K, Jayaraman S, Kyamanywa P et al. Building research capacity in Africa. Equity and global health collaborations. PLoS Med 11(3): e1001612. doi:10.1371/journal.pmed.1001612

sex with men (MSM) and prisoners in eastern and southern Africa (ESA). Within the portfolios there are four separate research programmes on adolescent HIV prevention, three on MSM HIV prevention, and one on prisoners (TasP). They are mainly formative and operational research. In addition to these eight research programmes, EHPSA has also funded a series of critical reviews that examine broader issues and aim to stimulate discussion and debate.

## 3. HIV RESEARCH AGENDAS AND PRIORITIES

### 3.1. Context

#### 3.1.1 Regional context

In addition to great differences in politics, economy and population size, the HIV/AIDS scenario varies considerably across the six countries. Swaziland continues to face HIV prevalence above 25% of the population (ages 15 to 49 years), in comparison with Kenya and Tanzania where HIV prevalence is below 10%. HIV prevalence in South Africa, Zambia and Malawi ranges from 11 to 19%. The ESA region also has a great variation in capacity to address HIV prevention efforts at national level.

Key populations suffer from adverse legal and human rights environments in all countries in the region. For example, homosexuality is criminalised in all countries except South Africa. The table below gives an overview of the legal framework for key populations in the six countries.

**Table 1: Overview of Legal Framework in six ESA countries**

Country	Decriminalisation of MSM/LGBTI	Debate on decriminalisation of sex workers	Harm reduction approach to PWID
Kenya	No	Yes	Yes
Malawi	No	No	No
South Africa	Yes	Yes	Yes
Swaziland	No	Yes	No
Tanzania	No	Yes	Yes
Zambia	No	Yes	unknown

While there has been an intense focus on HIV prevention and adolescents in recent years, the discourse is still affected by adult views on adolescent sexuality, as well as legal issues around age of consent (including for HIV testing and prevention programmes).

#### 3.1.2 Policy landscape

##### *National AIDS Councils*

All six countries have well-established national AIDS councils, or national AIDS commissions (NACs), that play a prominent role in developing policy and coordinating a multisectoral national response to HIV and AIDS. NACs are often established as separate entities, falling under the ministry of health or the prime minister/president's office, and have some freedom to work with key populations, despite the existence of unfavourable legal frameworks. Reasons for this include:

- Public health: The HIV epidemic is a public health concern. If countries are to meet internationally agreed targets they need to target key and vulnerable populations to reduce new infections.
- Constitutional mandate: National constitutions oblige governments to provide access to health services for all citizens without discrimination; and
- Donor funding: Most ESA countries are recipients of high levels of donor funding, some of which is conditional upon working with key and vulnerable populations.

*National HIV strategic plans*

Despite the adverse legal environment noted above, all six countries have national HIV strategic frameworks or plans (NSF,NSP) that include adolescents and key populations. All these plans identify sex workers, people who inject drugs, men who have sex with men and prisoners as key populations who, along with adolescents, are to be targeted with HIV prevention activities.

However, there are large differences in the scale and scope of HIV prevention strategies for KVPs in the six countries.

In addition to NSPs, some countries have policies and plans specifically for key populations and vulnerable groups.

- **Kenya** was the first country in the region to develop a strategic plan for a key population, sex workers. The policy for sex workers in 2010 was followed, in 2014, by the National Guidelines for HIV/STI Programming with Key Populations. In 2015, the Kenya NAC (NASCO), launched Kenya's Fast-track Plan to End HIV and AIDS Among Adolescents and Young People.
- The NAC in **South Africa** (SANAC) launched the South African National Sex Worker HIV Plan 2016-2019 in 2016, and the South African National HIV LGBTI Plan 2017-2022 the following year. The South African National Adolescent and Youth Health Policy was also launched in 2017.
- In September 2014 the Ministry of Health and Social Welfare of **Tanzania** launched the National Guidelines for Comprehensive Package of HIV Interventions for Key Populations. Tanzania also hosted the first two African key populations conferences (2013 and 2015). However, the current political environment in Tanzania is no longer supportive of programming for MSM.

While the existence of these structures and plans bode well for strengthening policy and programming for KVPs, the case of Tanzania shows that there is always the possibility that changes in government can reverse policy and curtail programming progress.

**3.1.3 Research landscape**

All six countries in this study have national research centres and ethical clearance bodies. However, research capacity varies widely across the countries.

Kenya and South Africa have relatively strong academic traditions and have been involved in cutting-edge HIV research since the early days of the epidemic, which has shaped policy and programming. For example:

- Kenya has a number of centres for HIV research based at universities, government facilities and part of international collaborations. These include one government body, two at the University of Nairobi, and three international research institutions.
- South Africa has a large number of centres for HIV research, many linked to universities across the country. Local researchers have good access to the global HIV scientific arena and actively participate in south-north and south-south research partnerships. Researchers based in leading US and UK universities are engaged in HIV prevention research, including for key populations.

Malawi and Swaziland have a comparatively modest national research capacity, each having only one public university. Much of the research on HIV prevention in these countries is conducted by international researchers and agencies, though in Swaziland the NAC commissions some HIV research.

Research capacity in Tanzania and Zambia falls between these two extremes: both countries have several centres or institutes conducting HIV prevention research, along with a number of international research agencies.

*Data repositories*

None of the six national governments has an overview of the HIV research in its country in the form of an up-to-date data repository. The situation varies according to country:

- Malawi has an online database of HIV research initiatives for the dates 1994-2007 that contains information of studies relating to research on sex workers, and adolescents, but nothing on prisoners, MSM or PWID. The NAC is planning a new digital repository.
- The South African National AIDS Council (SANAC) is planning a new digital repository for HIV research.
- Kenya has launched Maisha Maarifa, an online HIV knowledge research hub that aims to become a centre of excellence in translating research results into policy and practice.

### *Funding for research*

Domestic funding for HIV research is very low in all six countries, including Kenya and South Africa. Funding from the US government, particularly PEPFAR, and the Global Fund make up about 90% of research funds at country level. Donor-funded research institutes may work closely with the NACs but may not propose topics outside the scope of international donor interests.

There is recognition in all countries that, without a substantial increase in domestic funding for HIV research, it will not be possible for NACs to set their own research agendas.

### **3.1.4 Key research stakeholders**

In addition to the NACs and government ministries described in 3.1.2 above, there are several key stakeholders that influence HIV policy, programming and research initiatives in the region. These are:

- **Researchers:** It is common for there to be long-standing and established collaborations between renowned universities and research institutes in the global north and local counterparts. In addition to the evidence produced by research, many institutes run clinics, as part of operational research programmes, and the learning here is influential on programming and policy.
- **Donors:** The HIV field is unique in terms of the scale of international funding for both research and programmatic interventions. The Global Fund and PEPFAR constitute the largest donors in the six countries. Smaller donors include DFID, NORAD and the EU.
- **Multilateral agencies:** Agencies such as UNAIDS, WHO and UNODC provide normative guidance and technical support to countries in the region.
- **Implementing organisations:** Skilled and experienced non-governmental organisations provide many of the HIV prevention services in the region. These include international organisation such as Population Council, Family Health International (FHI) and International Centre for AIDS Care and Treatment Program (ICAP). Some of these agencies have research components and/or work in partnership with researchers.
- **Civil society:** Key population organisations, particularly for sex workers and MSM/LGBTI, are present in most ESA countries. These organisations represent their constituencies at local, national, and international levels, for advocacy, policy making, and programming. Many have strong reciprocal relationships with researchers: they provide access to their networks, influence research, and assist with dissemination of research findings. South Africa and Kenya have strong KP organisations for MSM, LGBTI and sex workers. This sector is relatively weak in Swaziland and Malawi.

## **3.2 HIV prevention research for key populations**

### **3.2.1 National HIV research priorities and agendas for KVPs**

Of the six study countries, only Kenya has a current national HIV research agenda. The Kenya HIV and AIDS Research Agenda 2014/15 to 2018/19, was launched as part of the National Strategic Framework in 2015. It aims to guide HIV research and research priorities for the following five years; to facilitate coordination of HIV research among stakeholders and to serve as a tool for resource mobilisation and allocation for HIV research. Research priorities for key and vulnerable populations include *inter alia* improving size estimates, evaluating effectiveness of structural and other interventions; determining transmission rates among adolescents; investigating mental health issues among adolescents and key populations; and reviewing legislation that impacts on access to HIV and SRH services. Prisoners are only referred to indirectly as part of priority populations.

Three of the other six countries are developing HIV research agendas. Others operate with broad research streams identified as part of the national AIDS strategic plan (South Africa); or with research priorities being part of the general health policy (Malawi and Swaziland). In more detail:

- **National HIV research agendas:** **Tanzania, Zambia and South Africa** are at various stages in the process of developing new national HIV research agendas aligned with their current national strategic plans.
- **National health research agendas:** **Swaziland** has followed a 15-step process to develop its first National Health Research Agenda (2014-2018). HIV/AIDS was identified as the most important focus area with themes for key populations and adolescents, including burden and determinants of HIV among adolescents and key populations; determinants of transmission among KVPs; and availability and equity of services. **Malawi's** national health research agenda specifi-

cally mentions research on the role of high risk groups (SW, MSM, PWID) in HIV transmission and prevention; determinants of, and trends in sexual risk behaviour in adolescents; efficacy and feasibility of novel interventions for HIV prevention; and effectiveness and impact of behaviour change interventions.

- HIV research agendas for one key population: In **South Africa** both the National Sex Worker Plan and the LGBTI Plan acknowledge evidence gaps and call for implementation and other research, though neither provides a clear research agenda.

### 3.2.2 Coordination of HIV research

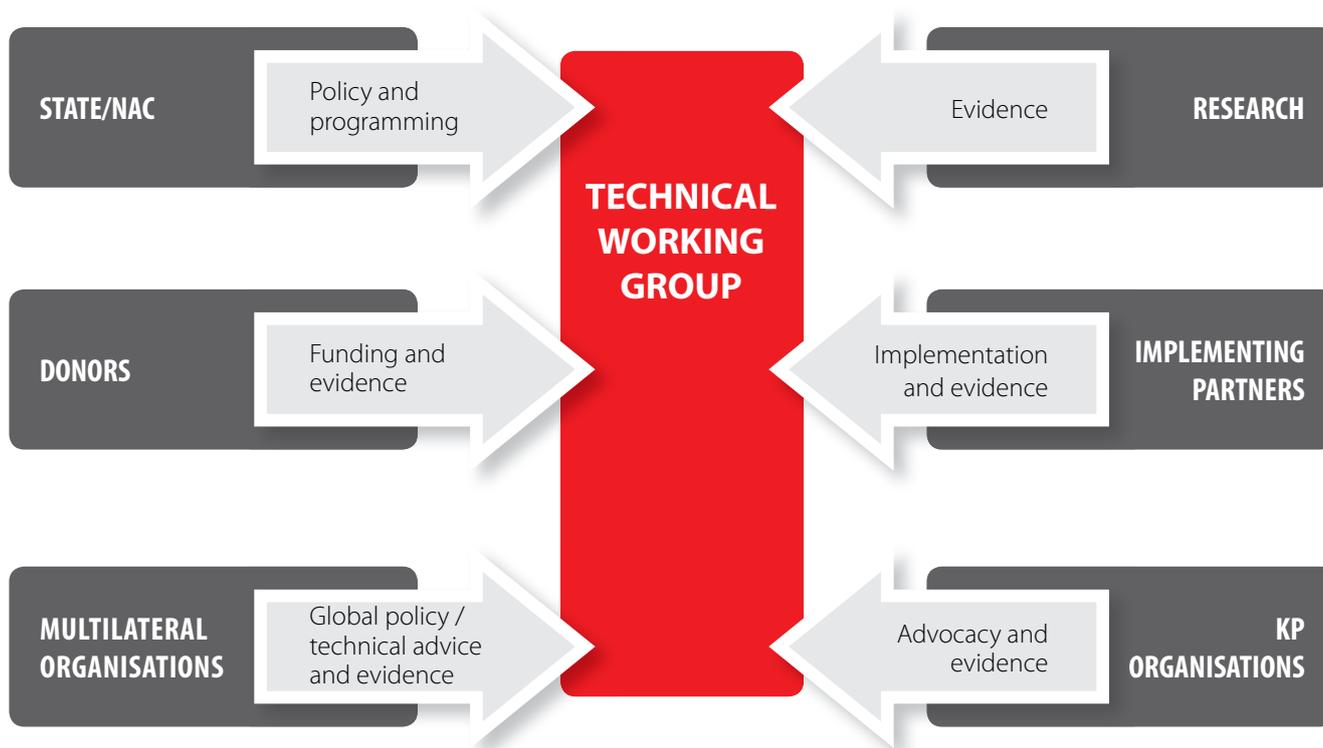
As noted above, all six countries have functional NACs to coordinate their HIV response. Each of these have a number of technical working groups (TWG) that cover key areas of HIV, such as prevention, treatment and care, key populations and research. These are multisectoral groups and include representatives of government as well as all major stakeholders identified in above.

Four out of the six countries (South Africa, Kenya, Zambia and Tanzania) have TWGs for HIV research.

The TWG is a forum where the main actors can identify knowledge gaps, recommend research, and discuss implications of research results. TWGs have been part and parcel of the national HIV response for many years. For example, in Kenya, a TWG on key populations was established in 2008 and has held quarterly meetings for a decade. This has built good relationships between representatives of the various actors.

The performance of TWGs differs widely both within and between countries, but in some instances, they have been critical forums for policymaking and coordination. Figure 1 below illustrates the six main stakeholder groups who attend the TWGs, and the different contributions they make.

**Figure 1: The six main actors and their contribution to TWG**



The six stakeholder groups each have specific areas of expertise that could enable the TWG to come to an informed position on HIV research needs. The inclusion of donors and researchers also facilitates an understanding of research gaps as well as research areas that are oversubscribed.

Thus, it can be seen that, in an ideal world, a TWG is the most efficient institution for setting national HIV research agendas and alignment of research with national priorities for adolescents and key populations.

Table 1 in the Annexures on p 16 gives a summary of findings on national policy and research in the six study countries.

## 4. KEY POPULATIONS AND HIV RESEARCH

This section of the paper draws on a large number of interviews with KP representatives in the six countries of Kenya, South Africa, Tanzania, Zambia, Malawi and Swaziland, with a particular focus on KP organisations relevant to EHPSA-supported research. It looks at issues relating to engagement of key populations in HIV prevention research at various levels and stages of research. These include engagement in shaping national research agendas as well as engagement during different stages of the research continuum.

From the interviews it is clear that KPs have important contributions to make to research. Firstly, KPs have insider knowledge about attitudes to HIV prevention, sexual practices, and the needs of their constituency, which is valuable for informing research. Secondly KP organisations can assist researchers with access to research subjects, which is a major challenge with 'hidden populations'.

On their part, KPs may be motivated to engage in research by other considerations, such as gaining access to health services, employment and learning new skills. In addition, there is a growing notion of research initiatives as not just platforms for knowledge generation, but also for capacity building and empowerment of marginalised populations.

### 4.1. National research agendas

The study has found that key populations organisations in some countries, such as Kenya and South Africa, had some influence on national HIV research agendas, and their implementation, through their participation in the relevant technical working groups (TWGs) of national AIDS commissions (NACs). In countries such as Malawi and Swaziland, where research agenda-setting has been led by ministries of health, key populations have not been engaged and their interests have been represented by international stakeholders.

In some countries, key population organisations have been able to influence the research agenda through participation in the development of new national strategic frameworks. For example, in Zambia, the engagement of an LGBT organisation Friends of Rainka, led to the recognition of MSM and transgender persons in the national HIV strategic framework.

In general, however, it would be safe to say that government bodies and donor agencies lead the development of national HIV research agendas and key populations play a limited role.

#### *Donor research agendas*

Donor agencies engage KPs to various degrees when drawing up their funding and research plans in countries across the region. A 2016 rapid review by leading African KP organisations<sup>3</sup> found that engagement levels were significantly higher for Global Fund concept notes than they were for PEPFAR country operational plans (COPs). Of 99 KP representatives, 33% of survey respondents reported that they had ever been consulted for a Global Fund concept note, compared to just 19% who had participated in a PEPFAR COP. Engagement fell off rapidly throughout the "engagement cascade" with under 8% saying they had made input into budgets.

When donors are designing research programmes, key populations may be consulted at an early stage when the business case or terms of reference are being drawn up. As in the case of EHPSA, these consultations are not likely to be followed through with the same organisations.

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<sup>3</sup> Esom K., Mubanda C., Khositau T., & Ogotu D., 2016. African Key Populations' Engagement with Global Health Financing Institutions: A Rapid Review. Johannesburg: African Men for Sexual Health and Rights (AMSHeR)

## 4.2. Engagement throughout the research continuum

KP organisations can be engaged at various stages of the research continuum. These are: conceptualisation and design; implementation; data analysis, dissemination and use of research results (evidence into action, EiA). The EHPSA case study in 4.3 below illustrates a typical example.

### *Good participatory practice (GPP)*

Global guidelines lay out principles for engaging stakeholders in HIV prevention research<sup>4</sup> and provide an ethical framework for developing effective engagement. Trial participants are at the heart of this framework, though stakeholders may be much broader, encompassing all who are affected by the research. This includes community, national and global stakeholders. These guidelines link meaningful engagement of KP organisations in research with community empowerment, and acknowledge the link between research and intervention, or service provision.

Building research competency is one of the guiding principles in GPP as this enables stakeholders to provide meaningful input into the research process.

### *Engagement modalities*

Community advisory boards (CABs) are the most common modalities for engaging KP organisations throughout the research continuum. The role of the CAB is to link the research with affected communities and ensure that stakeholders who will be affected by the research are represented and continuously informed about progress and results. This link is essential to ensure trust and collaboration, and avoid unnecessary misunderstandings and other obstacles to the research process. This is especially relevant for KPs, who are socially and politically marginalised, with few channels to effectively represent their interests.

Advisory committees may also present opportunities for effective KP engagement. For example, in Kenya, the Gay and Lesbian Coalition (GALCK) was supported to set up an LGBT research advisory committee, G10, which has developed a roadmap or pathway to achieve meaningful community engagement and ownership in research. It has become an important player in national research on KPs. The G10 is also represented at the National MSM Health Research Consortium, which advises and assists the Kenya Ministry of Health.

Other less commonly used engagement modalities include stakeholder engagement plans and technical forums. These are illustrated in the EHPSA Case Study below.

## 4.3. The EHPSA case study

This case study looks at engagement of KP organisations in EHPSA research programmes through six stages of the research continuum – concept and design, implementation, data analysis, dissemination and research uptake or evidence into action (EiA). It covers two key populations – MSM and prisoners – in three EHPSA research programmes, in the countries of South Africa, Kenya and Zambia.<sup>5</sup>

The two KP groupings differed considerably, with MSM KPs being well-organised and having the capacity to engage in policymaking and programming, as well as human right-based advocacy.

The table below summarises the findings in relation to engagement of key population organisations in various stages of the research process in four EHPSA research programmes.

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4 Key guidelines include: amFAR et.al. Respect, protect, fulfill. Best practices guidelines in conducting HIV research with gay, bisexual, and other men who has sex with men (MSM) in rights-constrained environments (2015), UNAIDS and AVAC Good Participatory Practice Guidelines for biomedical HIV prevention trial (2011), FHI 360 Stakeholder Engagement Toolkit for HIV Prevention Trials (2012).

5 See Table 2 in Annexures

**Table 1: Engagement of KP organisations in stages of the research process**

	Concept and design	Implementation	Data analysis	Dissemination	Use of research (EiA)
MSM/Kenya (Anza Mapema)	No	Yes	Yes	Yes	Yes
MSM/Kenya (TRANSFORM)	No	Yes	Yes	Yes	Yes
MSM/South Africa (Together Tomorrow)	No	Yes	Yes	Yes	Yes
Inmates/Zambia (TasP)	No	Yes	Yes	Yes	No
Inmates/South Africa (TasP)	No	Yes	Yes	Yes	No

*Conceptualisation and design*

None of the organisations had been engaged in the concept and design of the research, as would be expected in academic-led, donor-funded research programme. This was generally not viewed as a problem by the KP organisations interviewed. However, lack of involvement in the design phase did lead to some conflict during the implementation of one of the programmes.

*Implementation*

At the research implementation stage KP organisations were engaged in two main ways – recruitment of research participants and community advisory boards (CABs). Some researchers have commented that input from the CABs played an important role in the early stages of implementation, which led to adjustments in the programme design.

The TRANSFORM programme in Kenya has formally employed representatives of KP organisations, which has allowed for greater KP engagement at close hand.

In two of the projects, the quality of KP engagement was strengthened by institutional links to KP organisations. Anza Mapema<sup>6</sup>, in Kenya, set up an NGO for research participants; and Together Tomorrow had a formal relationship with KP organisations in KwaZulu Natal and Namibia, who were implementing partners for the research.

Other engagement modalities during the implementation stage that were supported by the EHPA programme included:

- Technical forums: A technical forum<sup>7</sup> was held for the three EHPA MSM research programmes in the region which brought researchers, policymakers and KP organisations in the region together to discuss research findings and potential EiA strategies.
- Stakeholder engagement plans: At the beginning of the implementation phase, EHPA supported researchers to develop comprehensive plans to engage KPs and other stakeholders throughout the research continuum.

*Data analysis*

All the EHPA research programmes have engaged KP organisations in data analysis. Researchers and KP organisations alike appeared to agree that the level and the mode of engagement were mutually beneficial.

*Dissemination and EiA*

All research programmes have plans to engage the KP organisations in the dissemination of the research results to the affected community and other relevant stakeholders in the locality. However, there were

6 Find out more at <http://www.ehpsa.org/research/msm/anza-mapema>

7 Find out more at <http://www.ehpsa.org/evidence-into-action/ehpsa-events/msm-forum-2017>

differences according to the characteristics of the key population. For example, prisoners would only be able to disseminate results in a stakeholder meeting inside the facility, due to the physical restrictions of a prison context. On the other hand, MSM organisations do not face similar restrictions and, as these organisations are generally well organised, they were seen as obvious partners for dissemination of research results. From their point of view, such dissemination was part of their advocacy for policy change and their own programming.

#### *Research literacy and mentoring*

Two EHPSA research programmes have strengthened KP organisation engagement by providing mentoring and training. The TRANSFORM programme in Kenya has provided research literacy training for the G10 KP research organisation. The Human Sciences Research Council (HSRC), who led the Together Tomorrow study, has provided technical support and mentoring to its two NGO implementing partners, who in turn have appreciated the opportunity to reflect, learn and publish from their experience.

## **5. CONCLUSIONS**

### **5.1. Alignment of KVP research to KVP policies, research agendas and priorities**

The prospects for research for key and vulnerable populations to be aligned with national needs, research agendas and priorities are generally weak but vary across the six countries.

Firstly, it is only possible to align research with national priorities when those priorities have been identified and fully spelled out in the form of an HIV research agenda. As we have seen, Kenya is the only country of the six that has a fully articulated HIV research agenda for KVPs. Research agendas for key populations and adolescents in the other five countries are either in development or are incomplete. Secondly, in four of the six countries, research capacity is modest and this limits the agency of national actors. Thirdly, in all countries, there is a predominance of donor-led research programmes driven largely by global priorities, which may or may not align with the priorities of the countries in question.

### **5.2. The ability of national governments to lead research for KVPs**

Turning to the question of the ability of national governments to lead and set their own research agendas for key populations, a more complex answer is found.

All six countries have fully articulated national strategic plans that include key populations and adolescents. They also have appropriate institutional infrastructures, in the form of TWGs, for setting research priorities and coordinating research. However, adverse socio-legal environments, particularly for key populations presents a major obstacle for state actors to be proactive in this regard. The lack of domestic funding for research is another serious obstacle to national agenda-setting. On the other hand, in some countries, there is a strong sense that donor-driven agendas have been critical in stimulating research and programming for key and vulnerable populations.

A repository of past and current HIV research is an important resource for planning and setting research agendas. However, Kenya is the only country of the six reviewed that has an established digital repository for HIV research.

### **5.3. The engagement of KP organisations in setting national research agendas**

KP organisations may contribute to setting national research agendas through their participation in the technical working groups of the national AIDS councils, or through their engagement in formulating national stra-

tegic plans. However, in general, government bodies and donor agencies lead the development of national HIV research agendas and key populations play a limited role.

#### **5.4. The engagement of KP organisations in the research process along the research continuum**

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There is growing recognition of the mutual benefits, for researchers and KPs, that may be derived from KP engagement throughout the research continuum. Findings from the EHPSA case study suggest that:

- Few if any KP organisations are engaged in the **conceptualisation and design** of research.
- The key ways KP organisations are engaged during the research **implementation** stage are recruitment of research participants and community advisory boards (CABs).
- KPs can make valuable inputs during the **data analysis** phase.
- KP organisations are obvious partners for **research dissemination and EIA**.
- **Research literacy training and mentoring** are ways of strengthening KP engagement in research.
- KPs may make an important contribution to research through dedicated **KP research advisory groups**.

The EHPSA programme has pioneered some innovative modalities for KP engagement. These include working closely with KP organisations as research partners, establishing dedicated KP organisations for research participants, and supporting stakeholder engagement plans.

## 6. ANNEXURES

**Table 1: Summary of findings on national policy and research in the six study countries**

	Kenya	Malawi	South Africa	Swaziland	Tanzania	Zambia
National AIDS Council	Yes	Yes	Yes	Yes	Yes	Yes
National AIDS Strategic Framework (NASF)	2014/15-2018/19	2015-2020	2017-2022	2014-2018	2013/14-2017/18	2017-2021
National HIV research agenda	Yes	Planning stage	In progress	No	Planning stage	In progress
KP Policy	Yes, 2010, 2014; sex workers, MSM, and PWID	No, MSM, sex workers, and prisoners recognized as KP since 2011	Yes, Sex Worker 2016, LGBTI 2017	Yes, 2013, MSM, sex workers, PWID, prisoners	Yes, 2014, Revised policy 2016	No, MSM and TG recognized KPs in current NASF
TWG on KP	Yes	Yes	Yes	Yes	Yes	Yes
TWG on research	Yes	No	Yes	No	Yes	Yes
Research councils	Yes	Yes	Yes	Yes	Yes	Yes
Ethical clearance bodies	Yes	Yes	Yes	Yes	Yes	Yes
Digital repository of HIV research	Launched in 2016, not yet fully updated	In Progress	In progress	No	No, rejected UNAIDS proposal	No
Research institutes with international HIV research partners	Many	Few	Many	None	Few	Few

**Table 2: Overview of the RRIF projects reviewed**

Name of research project	Project sites	Project sites visited	Key Pop
The Burden of Sexually Transmitted Infections among MSM in Kisumu, Kenya	Kisumu, Kenya	Kisumu, Kenya	MSM
Understanding the HIV prevention needs of MSM and their partners in Southern Africa	Pietermaritzburg, SA Windhoek, Namibia	Pietermaritzburg, South Africa	MSM
Targeted Research Advancing Sexual Health for MSM	Hillbrow, South Africa Nairobi, Kenya	Nairobi, Kenya	MSM
Treatment as prevention in correctional facilities in Southern Africa	South Africa and Zambia	Lusaka, Zambia and Johannesburg, South Africa	Prisoners

This document has been prepared as part of the Evidence for HIV Prevention in Southern Africa (EHPSA) programme which is supported by UK aid from the Department for International Development (DFID) and Sweden, through the Swedish International Development Agency (Sida) - mandated to represent the Norwegian Agency for Development Cooperation (NORAD)

The content and opinions as expressed within this document are those of the authors and do not necessarily reflect the opinion of UK aid, DFID, Sida, NORAD or that of the programme managers, Mott MacDonald

**ehpsa** is funded by UK aid and managed by Mott MacDonald [www.ehpsa.org](http://www.ehpsa.org)  
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