

# Nothing for us without us

Key population engagement in HIV research  
in eastern and southern Africa

## Introduction

The experience of the EHP SA programme has taught us that key populations (KPs) have an important contribution to make to HIV research. Both KPs and researchers have a strong interest in meaningful engagement and ownership of KPs in research about topics that concern them. It is widely recognised that this engagement, at all stages of the research continuum, can improve the quality of research.

EHP SA commissioned the Nordic Consulting Group to research the role of key populations in HIV prevention research, using the EHP SA programme as a case study. NCG interviewed over 100 research stakeholders in the ESA region. The main focus was on two KPs - men who have sex with men and inmates - in three research programmes in South Africa, Kenya and Zambia.

Discussion papers and other information is available <http://www.ehpsa.org/critical-reviews/hiv-prevention-research>. More information on the research programmes is available at <http://www.ehpsa.org/research/msm>.

## Why engage KPs in research?

Engaging KPs in HIV prevention research for KPs has strong mutual benefits for researchers and KPs.

*Benefits for researchers:* KPs have insider knowledge about attitudes to HIV prevention, sexual practices, and the needs of their constituency. All of this information is extremely difficult for outsiders to access due to limited trust and the delicate nature of the topical field. On a practical level, KP organisations can assist researchers with access to research subjects, which is a major challenge with 'hidden' populations.

*Benefits for KPs:* KPs benefit from knowing that research is correctly targeted, and therefore able to produce meaningful results that are useful for advocacy and programming. KPs may also be motivated to engage in research by other considerations such as gaining access to health services and 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.

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### Can KP organisations influence national HIV research agendas?

The key populations organisations in our study said they 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). TWGs are multisectoral bodies that bring all stakeholder groups together on particular subjects - such as HIV prevention, KPs and research - to share information and contribute to policy and programming.

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

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

Key population organisations can, and should, be engaged at all stages of the research continuum

### What modalities support KP engagement in the research process?

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, strengthen collaboration, fight myths and avoid unnecessary obstacles to the research process.

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 used by the EHPSA programme include:

- Technical forums: A technical forum was held for the three EHPSA MSM research programmes. These brought researchers, policymakers and KP organisations in the region together to discuss research findings and potential strategies to get research evidence into policy and programming.
- Stakeholder engagement plans: At the beginning of the implementation phase, EHPSA supported researchers to develop comprehensive plans to engage KPs and other stakeholders throughout the research continuum.
- KP employment: The TRANSFORM programme in Kenya has formally employed representatives of KP organisations, which has allowed for greater KP engagement at close hand.



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- Institutional links: The Anza Mapema research programme in Kenya set up an NGO for research participants. The Together Tomorrow research programme established a formal relationship with two KP organisations in Namibia and KwaZulu, who were implementing partners for the research.
- Mentoring and training: The TRANSFORM programme in Kenya has provided research literacy training for the G10 KP research organisation. The HSRC has given 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.

### How can KPs contribute 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).

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 during other phases of the research, though the situation differs for MSM and inmates.

The table below summarises the situation in EHPSA research studies.

**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



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### *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.

### *Data analysis*

All the EHPSA research programmes have engaged KP organisations in data analysis. The researchers would present the data analysis either to the KP organisation or to the CAB who provided insight into the findings. Researchers and KP organisations alike appeared to agree that the level and the mode of engagement were mutually beneficial.

### *Dissemination and use of results*

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 differences according to the characteristics of the key population. For example, inmates would only be able to disseminate results in a stakeholder meeting “inside the walls”, due to the physical restrictions of a prison context. On the other hand, MSM organisations, which are generally well organised, 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 strengthening their own programming.

The engagement of KP organisations in HIV research can improve the quality of the research and bring benefits to KPs themselves

### **Conclusion**

The engagement of KP organisations in HIV prevention research can improve the quality of the research and also bring benefits to KPs themselves. Findings from the EHPSA case study suggest that:

- KPs may make an important contribution to national research agendas through TWGs and dedicated KP research advisory groups.
- Few KP organisations are engaged in the conceptualisation and design of research. This situation could be improved.
- The most common modalities for engaging KP organisations during the research implementation stage are recruitment of research participants and community advisory boards (CABS).
- EHPSA research programmes have employed some additional innovative modalities for KP engagement in research and these could be more widely used.