

# **Vision**

Africa Free of New HIV Infections

# **Mission statement**

Facilitate and coordinate African led advocacy for HIV Prevention Research towards ending the HIV epidemic in Africa



# Mapping the Field: An assessment of Civil Society Engagement in Biomedical HIV prevention Research Advocacy in Africa

June 2018



# **Table of Contents**

Background and Context	1
MAPPING STAKEHOLDERS	3
Review of the literature	4
Assessment Findings	6
ONLINE SURVEY	6
Participant Overview	6
Engagement with new NPTs	7
STAKEHOLDER INTERVIEWS:	8
ADVOCACY REFLECTIONS: CHALLENGES AND OPPORTUNITIES	13
Actions for an enabling environment	13
EXTERNAL ENABLERS	13
COUNTRY APPRAISALS	14
Participating organisations and mapped networks	15
Respondent Membership Networks and Civil Society Working Groups	16
Networks identified through desktop research	18

# **Executive Summary:**

### **Background**

he Africa Free of New HIV Infections (AfNHi) commissioned an assessment in order to map national civil society participation, capacity and interest in biomedical HIV prevention research advocacy in Sub-Saharan Africa. The aim of the assessment was to identify which countries proved to be the most enabling for civil society engaged in this advocacy.

While much has been researched about site level engagement, national level civil society involvement has enjoyed scant attention. This assessment adds to African insights into civil society participation across different new HIV prevention technologies (NPTs) and enablers/challenges for advocacy.

#### **Methods**

At baseline desktop research served to identify civil society formations prominently involved in national biomedical HIV prevention research advocacy. AfNHi steering committee members were tasked to provide information for between 3 and 10 national stakeholder organisations per country for participation in the assessment. The final country sample included participants from Botswana, Ghana, Kenya, Malawi, Nigeria, South Africa, Tanzania, Uganda, Zambia and Zimbabwe.

Stakeholder organisations completed a brief online survey, of which nearly a third agreed to participate in - follow-on in-depth semistructured interviews, administered face-to-face and over skype. Interviews with heads of CBO networks, health and social service providers, NPT advocates, programme implementers, academic researchers and, civil society representatives inclusive of key and vulnerable populations were recorded, transcribed and coded for thematic analysis.

#### **Findings**

#### Online survey

Research Awareness: More than half of all participants were either existing stakeholders or able to name research studies underway for vaccines, microbicides and long-acting PrEP. Participants were highly aware of, and involved in PrEP roll-out, accounting for two-thirds of the sample. A small minority of participants reported to be stakeholders across more than one prevention tool.

Capacity Building Interests: Participants were most interested in Consultations on new prevention research and roll-out efforts (83%), followed closely by Advocating for greater investment in research and Community engagement and participation in research to roll-out (76% respectively).

#### **Stakeholder Interviews**

Stakeholder interviews captured the different country contexts that civil society advocates operated in, inclusive of recommendations for improvements. Key themes emerging from the interviews:

- A. Successful country advocacy is characterised by collaborative multi-sector Platforms where a fully represented civil society and government are able to meaningfully engage around policy guidelines; community mobilisation and access to NPTs throughout the research life cycle.
- B. Key population advocates, service providers and community representatives face greater social and political barriers to meaningful representation and participation in state convened platforms for engagement around NPTs.
- C. Piecemeal funding for HIV prevention research advocacy was associated with the diminished reach, quality, and sustainability of interventions.
- D. Government buy-in and participation in HIV prevention research to roll-out studies was framed as a major enabler for successful HIV prevention advocacy, in particular with regards to discussions for future access of tools that are proven to be effective.

#### **Discussion**

The assessment identified a vibrant and diversely constituted civil society engaged in biomedical HIV prevention research advocacy in Africa. Kenya, South Africa and Zimbabwe emerged as particularly enabling environments from which to operate. Here, country participants were represented across all NPTs, reported representation and participation of key and vulnerable groups; demonstrated SRH-HIV service integration efforts, and evidenced large scale PrEP implementation with key and vulnerable groups.

The assessment also acknowledges the limitations of the analysis conducted including: desktop research limited by a lack of country level NGO directory information; reliability/verifiability of website information and; lack of mainstream coverage of health related advocacy efforts that narrowed the final sample size.

## Acknowledgements

The assessment would not have been possible without the strategic vision and guidance of the AfNHi Steering Committee and Secretariat. We would also like to sincerely thank all of the AfNHi members and civil society stakeholders who offered their time and in-depth insights in service of championing an African led HIV Prevention research advocacy agenda. Finally, the assessment would not have been possible without the generous technical and financial support of AVAC through Coalition to Accelerate and Support Prevention Research (CASPR) who funded the study and facilitated a webinar at the end of 2018 to share the key findings.

# **Background and Context**

he Africa Free of New HIV Infections (AfNHi) commissioned an assessment in order to map organisations in Sub-Saharan Africa conducting health related advocacy (HRA). The assessment sought to identify links and enablers for an expanded African led civil society network engaged in

biomedical HIV prevention research advocacy.

#### **Respondent Countries:**

- Botswana
- Ghana
- Nigeria
- Kenya
- Malawi
- South Africa
- Tanzania
- Uganda
- Zambia
- Zimbabwe

Country respondents participated in an online survey and in-depth semi structured interviews. These resulted in country level data in order to understand what kinds of advocacy organisations are engaged in; challenges and opportunities in existing advocacy programmes; knowledge awareness and engagement with different new prevention technologies (NPTs) and; capacity building needs and interests among respondents.

The report presents the assessment findings. These are organized into survey findings where respondents present their level of knowledge and reported engagement with different NPTs and PrEP roll-out and; capacity building interests.

Data from the stakeholder interviews are presented to provide an overview of existing advocacy activities undertaken by organisations; country level contextual insights into implementation; missing populations and mapping of network memberships.

The last part of the report presents internal and external enablers for a strong civil society network. Stakeholder interviews are drawn upon to frame internal and external enablers for a strong advocacy network. Finally a consideration for the proposed network structure is presented taking into account the capacity building and advocacy interests identified.

From the online survey; respondent countries were shown to be highly interested in joining an African-led advocacy network in biomedical HIV prevention research and roll-out. Among the survey respondents, knowledge and engagement with research to roll-out activities was balanced across countries with more than a third of respondents reporting to be Existing Stakeholders in HIV Prevention research to roll-out studies. When considered individually, PrEP roll-out had the greatest proportion of existing stakeholders as compared to any of the tools under review. Respondents were least likely to have knowledge or be an existing stakeholder in BNAbs.



Stakeholder interviews point to similar advocacy experiences that can be mapped across different country contexts. The ease or difficulty of doing advocacy in different contexts was less related to country of operation, than location and constituents of the organisation. Interviews point to a different operating context for organisations working with key and vulnerable populations, in particular for MSM – exacerbated in countries where these populations are socially and legally sanctioned. The proximity and quality of government

relations to civil society was also frequently raised.

In considering the case for supporting civil society networks, the Academy for Education Development (AED) sets out strategic impact areas well-matched to the existing benefits expressed through core group interviews as well as needs and interests raised in country stakeholder interviews. These highlight the strategic value that AfNHi can bring to the sector through an expanded membership network:-

1

## **Amplification of Citizen Voice**

- Forums for people to share experiences, expressed identities, discuss and debate needed changes and craft strategies for action;
- Protection for those who are otherwise vulnerable to exploitation, abuse, or retribution for speaking out;
- Jointly-governed bodies for coordinating campaigns and other kinds of joint actions;
- Legitimacy with policy makers and other institutional leaders in democratic contexts

2

# Enable service-providing civil society groups to increase their social development impact

- Linkages to facilitate communication and learning among groups and organisations with similar programmes
- Platforms to coordinated programmes, activities and resources of multiple groups and organisations to achieve shared policy or programme goals;
- Legitimacy with government and donors as accountable cost-effective vehicles for implementing social development policies and programmes that reach the most isolated or marginalised communities;
- Jointly-governed bodies for managing coordinated programme implementation, monitoring and evaluation.

## **Mapping Stakeholders**

Organisations were identified through desktop research using regional and national NGO directories, civil society research reports, and targeted searches according to populations groups prioritised through this review.

Data quality from desktop research into civil society organisations was constrained by a:

- Dearth of information points from which to gather data.
- Lack of detailed country level NGO directories.
- Language Limitations <sup>1</sup>
- Outdated directory and organisational website information which hampered secondary verification of data collected.
- Lack of mainstream media coverage of health related advocacy efforts, coupled with lack of detail.

At the baseline, AfNHi core group members located in Ghana, South Africa, Kenya, Nigeria, Malawi and Uganda populated a network mapping tool with information for between three to ten national level organisations for participation in an online survey and country stakeholder interviews.

In addition to the information provided by the AfnHI Core Group, the AfnHi Secretariat provided a regional database for participants from Botswana, Cameroon, Nigeria, Kenya, Malawi, Tanzania, Uganda, Zambia and Zimbabwe. These were further supplemented by stakeholders identified through desktop research.

Response rates among organisations identified through the online desktop research yielded low participation overall. Resulting participants in the online survey showed a high level of knowledge and engagement with HIV prevention research. This points to the need for improved linkages among organisations working in broader domains of HIV prevention and sexual and reproductive health and rights.

The table presented under Survey findings present an overview of participating countries and the thematic programme areas and populations groups represented for each country sample. Participating organisations and networks mapped are found at the end of the document.

<sup>1</sup> Limited to Anglophone countries

## **Review of the literature**

Practice Guidelines (UNAIDS/AVAC, 2011); an expanded framework of participation for civil society stakeholders in the design, monitoring and roll-out of NPTs. Efforts to integrate NPTs into the mainstream HIV prevention discourse in civil society has been bolstered through advances in PrEP licensure, a movement pushing for continued post-trial access, regulatory approval for the dapivirine ring<sup>2</sup> and; wide scale stakeholder mobilisation for vaccines.

2 CROI Update on the dapivirine ring (2018) https://www.ipmglobal.org/sites/default/files/media\_block\_files/dream\_release\_croi\_2018\_final.pdf

At the same time as the prevention toolkit expands, the momentum and popular support experienced in the civil society movement for access to treatment has not been seen for NPTs. The 2008/9 financial crises and subsequent reduction and centralizing of funds has advocacy weakened networks across engagement platforms. The next section briefly presents existing multi-country assessments undertaken that can be useful in understanding biomedical HIV prevention advocacy implementation in Africa.

In 2015 The AIDS Alliance conducted a civil society mapping of organisations in ten countries in Southern Africa, resulting in a directory of between 15 and 40 organisations in four countries working toward progressive access to essential medicines. The directory maps a wide range of civil society organisations including some network organisations and called for improved resourcing and capacity building for local service providers in order to contextualise community networks pathways to health access (Molokele & Mohammed, 2016).

A regional mapping of non-institutionalised mechanisms such as voluntary networks, working groups, coalitions etc. operating at national levels for biomedical HIV prevention research as a whole - was not found through desktop research. These less formalized structures, sometimes ad-hoc or goal-specific coalitions could offer insights into evolving advocacy emphases and prioritised populations. Information on individual networks and mapped memberships showcase an actively engaged civil society representing diverse and overlapping key and vulnerable populations (Molokele & Mohammed, 2016).

In 2017 the International AIDS Vaccine Initiative (IAVI) released an advocacy report considering the capacity of African CSOs to deliver and scale-up biomedical HIV prevention research advocacy efforts. The evaluation was focused on structures that received funding from IAVI with subsequent findings reflecting a four-year project review period, 2012-2016.

Report findings highlighted: (i) African CSOs have the capacity but lack the investments and resources to scale-up; (ii) Pursuing partnerships between scientists, African CSOs, community and stakeholder advisory groups are important for large-scale buy in (iii) The quality and sustainability of advocacy programmes are hamstrung by the absence of long term and short term funding opportunities for African CSOs; (iv) African CSOs and advocates need to develop their own monitoring and evaluation frameworks in order to measure and develop strategies aligned to their domestic contexts for better planning (IAVI, 2017).

These findings are supported in the AIDS Alliance mapping that recognize a vibrant network of CSOs working across different programme areas and linking up to national, regional and global networks in health (Moleleke & Mohammed, 2016). Civil society advocacy is ultimately strengthened where there is political will and national policy guidance. Engaging policy makers on national and regional decision making structures is a critical component of advancing the HIV prevention research agenda overall.

Ephsa (2015) undertook a review with policy makers to map enablers for securing political will and participation by states to act on HIV prevention evidence. Policy makers put forward that they (i) favoured domestic research where they were involved at inception (ii) experienced a perceived lack of interest in engagement by researchers (iii) sought a series rather than once-off engagements; (iv) needed diverse and contextual information packages and; different modes of engagement including face-to-face

and online (Ephsa, 2015). With adequate resourcing, local CSO are well-placed to develop programmes to respond to these needs and challenges (Molokele & Mohamed, 2016).

A 2015 IAVI policy brief outlining how to approach research and development of NPTs for women and girls, set out a synergistic set of recommendations that provide a bridge for civil society to engage policy makers. The policy brief specifically highlighted the need to invest in and act on social science research; incorporate health and science literacy into research programs; align research efforts with programmes addressing social and economic issues and, ensure the sustainability of community benefits (IAVI, 2015).

Existing research presented provide a set of themes and actions that have been identified as determinants in the success of HIV prevention research advocacy agendas. The need for greater resourcing and capacity strengthening of civil society was highlighted throughout. None of the research provided insight into existing levels of knowledge or engagement of CSOs with NPTs as a whole. Similarly there is a dearth of qualitative data that privileges the voices and experiences of CSO implementers in framing what they feel are enablers for the advancement of biomedical HIV prevention research advocacy from their perspectives.

# **Assessment Findings**

he online survey was a brief five question survey in order to gauge self-reported knowledge and interest in biomedical HIV prevention research advocacy by organisations identified through the situational analysis. The online survey was circulated among country stakeholders and was used as a point of reference to identify participants for country stakeholder interviews.

The survey provided the following data points:

- Knowledge and engagement with NPTs
- Capacity building interests for scaled up advocacy
- Stakeholder organisations working in the region

## **Participant Overview**<sup>3</sup>

COUNTRY			PROGR	AMME A	REAS							<b>POPU</b> I	LATIC	ON GR	OUPS			
	Community Systems Strengthening	Health Advocacy/ Access	Health Promotion	Health Research	PrEP Roll- out	SRHR	Networks	HIVPrX	Women	Young Women	Young People	OVC/ MCH	Key Pop.	PLHIV	Sex Workers	MSM	LGBTI	Media
Ghana											1							
Kenya														1				
Malawi									1		1	1		1	1	1	1	1
Mali											1							
Nigeria											1							1
South Africa														1				
Tanzania																		
Uganda											1		1					
Zambia														1				
Zimbabwe										1				1				

 $<sup>3 \</sup>qquad \hbox{A list of participating organisations and mapped networks are presented at the end of this document}$ 

#### **Engagement with new NPTs**

Self-reported research awareness was moderately high with more than a third of all survey respondents identifying as existing stakeholders in HIV prevention research to rollout efforts in their respective countries. While the majority of stakeholders represented countries with HIV prevention research studies underway, respondents from Nambia, Nigeria and Ghana also identified as existing stakeholders – pointing toward involvement in efforts to scaled-up access to PrEP.

It stands to reason that the survey would attract those with an existing interest or involvement in HIV prevention research advocacy. What the selection thus demonstrates is that among civil society organisations that have an interest in HIV prevention research studies and access to NPTs; the greater proportion are able to access information and are actively engaged as stakeholders.

#### **Key Points**

- More than half of respondents were either 'Existing Stakeholder's or could name studies underway for vaccines, microbicides, long-acting PrEP and/ or PrEP Roll-out.
- Two-thirds of respondents were either 'Existing Stakeholders' or could name activities underway related to PrEP roll-out.
- Respondents were least likely to be 'Existing Stakeholders' for long-acting PrEP and BNAbs
- More than half of respondents had 'Very Little Knowledge' or 'No Knowledge' about BNAbs

- Reported knowledge and engagement with vaccines and microbicides was consistent across respondents.
- Respondents were highly aware and involved with PrEP rollout.

Survey respondents were knowledgeable about different NPTs tools overall. With the exception of BNAbs the largest proportion of respondents are either existing stakeholders or able to name existing activities underway in relation to vaccines, microbicides, long-acting PrEP and/or PrEP roll-out.

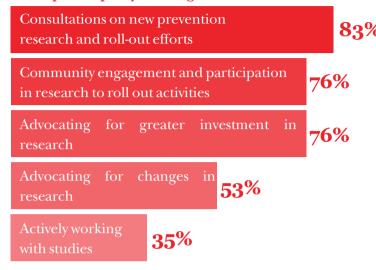
Respondents were least likely to have knowledge or involvement with BNAbs. While respondents who selected 'General Knowledge' was similar to that of other NPTs, the number of respondents who reported having 'No Knowledge' for BNAbs was more than double than the combined number of respondents who reported to have 'No Knowledge' or 'Very Little Knowledge' for any other tool. Country responses were balanced across the sample.

Country responses show a general awareness and moderate involvement with vaccines, microbicides and long-acting PrEP. Existing stakeholders for PrEP roll-out far outnumbered that of any other NPT. This could indicate that the point at which civil society are more actively engaged follo ws on from licensure.

Survey respondents were tasked to indicate their capacity building interests according to a set of options presented in the table below. Multiple selections were permitted.



#### **Participant Capacity Building Interest**



The largest proportion of respondents were interested in "Consultations on new prevention research and roll-out efforts". Stakeholder interviews unpacked some of the challenges experienced by civil society in accessing information at where local studies were at, as well as missed opportunities as a result.

"Community engagement and participation in research to roll-out activities" and "Advocating for greater investment in research" also emerged prominently in the online survey. Inputs around resourcing in stakeholder interviews point to a challenging environment. "Advocating for changes in research" and "Actively working with study sites" emerged as the area where respondents reported the least interest.

#### Stakeholder Interviews:

Stakeholders interviews mapped different kinds of biomedical HIV prevention research advocacy participants were engaged in ; associated challenges and opportunities and; proposed actions to achieve success.

Engagement can be broken down into 1) Implementation: where a respondent cites an example of an activity they have executed and 2) Capacity Building: different information platforms including workshops, conferences, and committees that a respondent has attended. The types of engagement cited by respondents are found below. The first column shows the types of implementation while the second column lists the Information and Consultation Platforms.

IMPLEMENTATION	INFORMATION AND CONSULTATION PLATFORMS			
Community Dialogues on HIV Prevention Research	Workshops, regional platforms with journalists from Lusaka,			
and NPTs	Zambia, Zimbabwe			
Community radio roadshows linking microbicides	Media Science café with scientists, journalists and activists in			
and women's SRH	Uganda			
Deletienshing with University research sites	AVAC Platforms (Civil society consultations, regional			
Relationships with University research sites	trainings and workshops)			
Direct, or network member participation in CAB	Multi-sector Advisory Committees for Implementation of			
Meetings (chairpersonships and general	PrEP			
memberships)				
Research literacy with community, media and	PEPFAR quarterly meetings			
government stakeholders				
Ad-hoc informal social media engagement on social	International AIDS Symposia			
media on different prevention tools	International AIDS Symposia			
AVAC Follow hosting exceptions	Amfer – American based data organization shares country			
AVAC Fellow hosting organisations	specific information			

Capacity building of media on vaccines	National Dialogue for AGYW on HIVPrX Options
Stakeholders in the design of PrEP demonstration projects	Microbicides Trial Network Meeting
Memberships in PrEP Working Groups (national & regional)	Technical Assistance from AVAC
PrEP Provision for Young Women and MSM	National Consultation meetings on Microbicides with youth; people with disabilities; adolescent girls and young women
Community preparedness and rights programmes with key populations for PrEP access	
Community engagement, policy advocacy for PrEP roll-out	
Science Cafes with Journalists, Scientists and Advocates for Vaccine	

The list above is an indicative list of activities that participants are actively involved in. Overall participants were shown to be highly involved in HIVPRX Advocacy within their communities, at national policy level, as well as engagement of broader stakeholders such as the media, key and vulnerable populations. Activities toward the advancement of PrEP advocacy for progressive access and scale-up was reported among all respondent countries in the online survey.

Respondents were able to link PrEP activities to other areas of their work. Pushing for the realisation of a particular health goal for key populations, or pushing for national guidelines and policy formed concrete social outcomes around which most activities were organised. Respondents who identified as stakeholders for PrEP roll-out were also more likely to have a focus on populations shown to be at higher risk for HIV such as MSM, young women, and sex workers in targeted areas.

National multi-sector advocacy programmes were characterised by technical working groups around PrEP, while other tools under study had less participation and engagement from government and broader HIV prevention advocates. Activities to raise awareness around microbicides included community mobilisation, national consultations and capacity building.

Stakeholders also reported on multi-sector national and regional engagement platforms around vaccines. Locally, capacity building of journalists and relationships with university research sites were named, while regional workshops brought opportunities for consultations and strategy development.

Stakeholder interviews followed the same pattern of engagement with different NPTs as reported for the online survey. engagement presented the most opportunities engagement comprehensive government and broader civil society buy-in. Country activities in support of microbicides and vaccines show broader stakeholder engagement, albeit without prominent government support. Dedicated activities for BNAbs and long-acting PrEP were not reported.



## **Advocacy Reflections: Challenges and Opportunities**

The next section begins with a critical reflection of the challenges in implementation as quoted in a stakeholder view. This is followed by the suggested actions for strengthening advocacy as identified by interview participants.

Advocacy is a long process, it is a tedious process. Advocacy efforts should result in changing mindsets of decision makers. And that does not come easy because it is about what people believe is right. Now you are coming in to influence their thinking; raising their consciousness and giving them evidence as to why you are proposing that what we think works. Political environment is conducive – but you need to know the stakeholders, have your evidence packaged well and see that it's not going to happen instantly.

I believe in advocacy, I believe that advocacy works, but I believe that we also need to understand that we are not going to put advocacy in a logframe there and it will all come up nicely. More and more there is limited funding because of how programmes have been framed, the majority of programmes are targeting numbers. But it is the soft way that will impact the work over time. As a donor you don't want to put money in a programme where you don't see results.

- How do we as civil society frame advocacy
- What are the milestones, how do we break it down,
- How do we develop our indicators so donors can begin to feel that that there is accountability and value in money for what it is that we do?

In our time there was support for how we did advocacy which took a long period of time. Today we need to think about value for our money; what do we share with the donor? Have to clearly define the ultimate goal we want to achieve and the key milestones to achieving this so that we can report in the most transparent accountable way.

If you want advocacy to remain a respectable domain, as civil society we need to work with universities and academics to develop indicators that programmers could use. What are the progress markers that we can look at, to know we are moving in the right direction?

Stakeholder Interview, Zimbabwe

Interview respondents considered enablers and barriers to successful country advocacy for NPTs. A few common themes emerged across stakeholder interviews – presented below:

# Theme

Successful country advocacy is characterised by collaborative multi-sector Platforms where a fully represented civil society and government are able to meaningfully engage around policy guidelines; community mobilisation and access to NPTs.

Where participants described advocacy as being easy, this was linked to examples of shared civil society and government engagement platforms. Enablers described by participants all point to a platform that is accessible, and where civil society are able to influence and input into government programmes and policies.

Involvement with PrEP implementation and roll-out from local to national policy development emerged prominently across survey and interview respondents. Respondents all characterised ideal civil society engagement platforms as spaces:

- Where civil society had the power to influence decision making in policy development
- Where government officials, administrators, political representatives were accessible to civil society
- Where civil society inclusive of key populations were well-represented
- Where NPTs were included in national strategy and policy documents

# Theme 2

Key population advocates, service providers and community representatives face greater social and political barriers to meaningful representation and participation in state convened platforms for engagement around NPTs.

Participants working with key and vulnerable populations as their primary constituents were more likely to express challenges in implementing advocacy programmes. In particular, legal criminalisation and social stigmatization of MSM was raised by respondents from Uganda, Tanzania, and Nigeria.

Extending from stigmatizing government attitudes to hostile social environments; challenging spaces for the representation of key populations were characterised whereby:

- Organisations had to apply for a permit from local government to host HIV prevention information sessions
- Organisations were deregistered because they represent MSM
- Broader civil society and service providers sideline MSM for fear of persecution of association
- Key populations are either not-represented at all or lacked capacity to meaningfully participate in policy consultation platforms
- Criminalisation of key populations prevents the development of progressive realisation of access to appropriate health services for key populations



# Theme 3

There is an interest and opportunity for strengthened community engagement for NPTs through greater involvement of advocacy networks across the research life cycle

Respondents could name different information sources for HIV prevention studies, but expressed the desire to get information from research sites in a more routinized relationship. This information was almost unavailable to community based stakeholder organisations outside of study sites. Reported relationships are ''participation by invitation", where civil society are convened for a purpose predetermined by researchers.

Similar themes emerged across all countries:

- Increased engagement with advocates located outside of the immediate research site by implementers will fast-track policy conversations and pave the way for future access
- A lack of locally available information on developments in research studies prevents opportunities for regional knowledge sharing and exchange among advocates
- When meaningfully engaged, civil society networks and advocacy organisations can act as a neutral accountability arm in the implementation of studies
- Massive knowledge gaps at community level persist, civil society have a role to play in feeding back to past trial sites, as well as affected communities and stakeholders outside of existing trial sites.

# Actions for an enabling environment

nterview participants were tasked to reflect on what they felt would contribute to an improved advocacy environment. Responses are organized into internal and external enablers. External enablers include changes in the government and research environments. Internal enablers reflected on skills building for advocacy organisations and how the AfNHi Secretariat could strengthen participation.

#### **External Enablers**

## Changes in research

Participants discussed the level of engagement with research scientists as varied and ad-hoc. Many of the participants who are active stakeholders in prevention research in particular, called for an expanded level of civil society engagement.

#### Recommendations:

- Stakeholder Engagement programmes must work with heads of CSO networks and build their capacity to understand HIV prevention research studies. With this knowledge they are then able to better advocate together with their constituents.
- CSOs want to play a greater role in implementation as well as greater access to information around how the research unfolds linking up to national and regional exchanges.
- There should be routinized feedback to civil society as with CABS. Community engagement has to
  extend beyond the research site, to include civil society at national level to drive advocacy at that
  level.
- Research literacy remains a challenge for wider civil society engagement, more visual aides are needed to overcome literacy limitations. Communication materials for research literacy need to domesticated and translated into simple accessible language.
- With demonstration projects underway targeting vulnerable populations, civil society have a role in adding a layer of accountability and support for stakeholders toward comprehensive access.

### **Engaging National and Regional Decision Makers**

Government buy-in and participation in HIV prevention research to roll-out studies was framed as a major enabler for successful HIV prevention advocacy, in particular with regards to discussions for future access of tools that are proven to be effective. In discussing challenges experienced in implementing HIV prevention research to roll-out advocacy, many participants also had actions for how the gap with government could be bridged.

#### Recommendations:

• Increase civil society participation in regional governance for a including the Economic Community of West Africa States (ECOWAS), East Africa Community (EAC) Southern African Development Community (SADC); and the African Union as whole to drive policy commitment for HIV prevention research and roll-out regionally.



- Increase government stakeholders' technical capacity to understand, engage and subsequently advocate for HIV prevention research and roll out tools and pathways.
- Increase work with policy makers to better define HIV prevention research in national HIV and AIDS policy documents and strategies so as to establish a point of engagement.
- Remove legislative barriers that curtail quality provision of information, services and commodities that undermine human rights for key and vulnerable populations.

#### **Resource Mobilisation and Investment:**

All respondents spoke of the difficulty in attracting and retaining funding for HIV prevention research advocacy. This was associated with the diminished reach, quality, scale-up and sustainability of HIV prevention research advocacy.

#### Recommendations:

- Establish a dedicated civil society advocacy fund for HIV prevention research to support longer term projects, spread across a range of countries - moving away from piecemeal funding focused around one prevention tool.
- Mobilise resources to expand the AVAC Fellowship: Thematic areas and hosting organisations could be identified within the AfNHI network. Increased resourcing for more targeted clustering of advocates according to sectors like media.

## **Country Appraisals**

From the convenience sample in the assessment, all countries demonstrated examples of HIV prevention research to roll-out activities. Zimbabwe, Kenya and South Africa emerged as the countries that demonstrated the most enabling environments for implementation of HIV prevention research advocacy activities. Countries demonstrated the following

- Largest number of existing stakeholders across respondents
- Representation of existing stakeholders across all NPTs
- Representation and participation of key and vulnerable populations
- Multi-sector civil society networks extending regionally and globally
- Enabling advocacy environment for civil society access and participation in the development of national health policy and programmes
- Evidence of SRH HIV service integration (SRH HIV Linkages Project)
- Civil society engagement and consultation platforms recognised as legitimate by the state
- Prioritisation of PrEP access and scale-up key and vulnerable populations including MSM, FSWs and young women
- Large scale PrEP Implementation

Botswana **PRIMARY** Kenva **SECONDARY** Tanzania Ghana South Africa FOCAL **FOCAL** Uganda Malawi Zimbabwe **COUNTRIES COUNTRIES** Zambia Nigeria

#### Participating organisations and mapped networks

- Ghana; Society for AIDS in Africa
- Ghana, Hope for Future Generations
- Kenya, International AIDS Vaccine Initiative (IAVI)
- Kenya, National Empowerment Network of PLHIV (NEPHAK)
- Kenya, Personal Initiative for Positive Empowerment (PIPE)
- Kenya, KEMRI-CCR PHRD (THIKA Project)
- Malawi, CEDEP/MANET
- Malawi, CEDEP
- Malawi, Health Rights and Education Programme (HREP)
- Malawi, Malawi Health Equity Network
- Malawi, Malawi Network of AIDS Service Organisations
- Mali, Change
- Nigeria, 3rd Sector Support Africa
- Nigeria, Institute of Human Virology
- Nigeria, Journalists Against AIDS
- Nigeria, New HIV Vaccine and Microicide Advocacy Society (NHVMAS)
- Nigeria, Relief and Hope Foundation
- Nigeria, SAM Empowerment Foundation
- Nigeria, Youth Builders Initiative
- South Africa, AIDS Foundation South Africa
- South Africa, Embrace Dignity
- South Africa, Emthonjeni Counselling and Training
- South Africa, Section 27
- South Africa, WACI Health
- South Africa, Wits Social Research
- South Africa, Women's Sector
- Tanzania, Health Promotion Tanzania
- Tanzania, Council for Social Development (TACOSODE)
- Tanzania, Tanzania Network of WLHIV and AIDS
- Tanzania, WAREMBO Forum
- Uganda, Coalition for Health Promotion & Social Development



- Uganda, People in Need Agency
- Uganda, Public Health Ambassadors Uganda (PHAU)
- Uganda, Uganda Preventative Care Intl.
- Zambia, Zambart
- Zambia, Treatment Advocacy and Literacy Campaign (TALC)
- Zimbabwe, Advocacy Core Team
- Zimbabwe, HIV/AIDS Activists Union Community Trust
- Zimbabwe, Zimbabwe Pangaea Zimbabwe AIDS Trust (PZAT)
- Zimbabwe, Zimbabwe University of Zimbabwe College of Health Sciences Clinical Trials Unit

## **Respondent Membership Networks and Civil Society Working Groups**

AFRICA HEALTH ACCOUNTABILITY PLATFORM, TANZANIA	REGIONAL COALITION OF CSOS WORKING IN HEALTH
Advocacy Core Team, Zimbabwe	National advocacy network of CSOs working in HIV and AIDS
Association of Civic Organisations (AZAKI), Tanzania	National umbrella of registered NGOs
Coalition for Access to Essential Medicines, Uganda	National Coalition that advocates for access to treatment and TasP
CSO Accountability Forum (CAF), Nigeria	National CSO-led forum working in HIV
Disability HIV/AIDS Trust (DHAT), Zimbabwe	National network advancing HIV and SRH issues for people with disabilities
Family Planning Technical Working Group, Tanzania	National forum for the advancement of family planning
GF Financing Facility, Tanzania	National coordination network for global fund recipients
Ghana HIV and AIDS Network (GHANET)	National network of CSOs represented on the Ghana AIDS Commission
Health Coordination Network, Kenya	National coordinating network for CSOs working in health
HIV Prevention Research Network, Kenya	National network of stakeholders working in HIV Prevention research
HIV Advocates Group, Uganda	National network of HIV advocates
Health Journalism Network Uganda	National network of journalists working in health
HMT - Action Partners, Tanzania	National coalition advocating for integrated HIV &TB response
Human Rights Working Group (coordinated by UAC), Uganda	National platform for monitoring human rights funds
International Community of Women living with HIV in Eastern Africa (ICWEA)	Regional advocacy network for WLHIV
IPHASA, East Africa	Regional coalition of health practitioners in East Africa
Kenya Health HIV CSO Platform	National network of CSOs working in health
Local Civil Society Prevention Coalition (formative), Uganda	National civil society platform for HIV prevention



AFRICA HEALTH ACCOUNTABILITY PLATFORM, TANZANIA	REGIONAL COALITION OF CSOS WORKING IN HEALTH
Malawi Network on New HIV prevention technologies	National network of stakeholders advancing HIV prevention technologies
National Forum for PHA Networks, Uganda	National umbrella organisation for PLHIV
National Council of PLHIV in Tanzania (NACOPHA)	National membership organisation for PLHIV
National RMNCH Working Group, Tanzania	Regional civil society coalition for RMNCH
National Prevention Committee, Uganda	National stakeholder HIV prevention platform hosted by UAC
Network of Women Living with HIV and AIDS (TNW+), Tanzania	National membership organisation for WLHIV
Network of people living with HIV and AIDS in Nigeria (NEPWHAN)	National umbrella organisation for PLHIV
New Prevention Coalition- coordinated by EANNASO , Uganda	Regional coalition coordinated by EANNASO working in HIV prevention
PHASA (Public Health Association South Africa )	National Network of public health associations and stakeholders
Policy Forum Tanzania	National nework of NGOs working in health policy
PrEP Task Team, Malawi	National network of stakeholders advancing PrEP access
PrEP Technical Working Group MOH, Botswana	National stakeholder around workign toward PrEP access
Regional Network in Equity in health in Eastern and Southern Africa (Equinet)	Regional network in East and Southern Africa advocating for social justice in health
PrEP steering Committee, East Africa	Regional coalition for the advancement of PrEP
Sisonke Sex Workers Movement, South Africa	National sex worker advocacy network
South Africa Health Technologies Advocacy Coalition	National network of CSOs working in health research and development
South African National AIDS Council (SANAC) Civil Society Forum	National network of CSOs represented on the South African NAC
Steering Committee for Key Populations, Uganda NAC	National platform for improved health for key populations
Technical Working Group for Key Populations MOH	National platform for improved health for key populations

AFRICA HEALTH ACCOUNTABILITY PLATFORM, TANZANIA	REGIONAL COALITION OF CSOS WORKING IN HEALTH
TB Forum, Kenya	National network of stakeholders working on issues of TB
Uganda Network of AIDS Service Organisations (UNASO)	National umbrella organisation for AIDS service organisations
Women Rising, Zimbabwe	National accountability forum for DREAM
Zimbabwe AIDS Network	National coordinating network for CSOs working in HIV and AIDS

# Networks identified through desktop research

NETWORK NAME	AREAS OF OPERATION			
African Civil Society Platform for Health	Pan African			
African Men for Sexual Health and Rights (AMSHeR)	Pan African			
African Women's Development and Communication Network (FEMENT)	Pan African			
International Community of WLHIV Eastern Africa (ICWEA_	Burundi, Kenya, Rwanda, Taznania, Uganda			
African Youth and Adolescents Network (AYAN)	Kenya			
African Youth Safe Abortion Alliance (AYOSA)	Botswana			
AIDS and Rights Alliance for Southern Africa (ARASA)	Southern Africa			
AIDS NGO network in East Africa - (ANNEA)	East Africa			
Botswana Network on Ethics, Laws and HIV/AIDS (BONELA)	Botswana			
Botswana Network of AIDS Service Organisaiton (BONASO)	Botswana			
Botswana Network of People living With AIDS (BONEPWA+)	Botswana			
Botswana Young Women's Network	Botswana			
CISHAN (Civil Society on HIV&AIDS) in Nigeria	Nigeria			
Coalition for African Lesbians (CAL)	Pan African			
Coalition for Gender, HIV and AIDS Advocacy in Malawi (COGHAAM)	Malawi			
The Coalition of Women Living with HIV and AIDS in Malawi (COWLHA)	Malawi			
Community Health Education Services & Advocacy (CHESA)	Tanzania			
Community Working Group on Health	Nigeria			
Federation of People with Disabilities, Malawi (FEDOMA)	Malawi			



NETWORK NAME	AREAS OF OPERATION
Gays and Lesbians Zimbabwe	Zimbabwe
Gay and Lesbian Coalition of Kenya	Kenya
Gender Coordination Network (GCN)	Ghana
Generation Initiative for Women and Youth Networks	Nigeria
Girls Empowerment Network	Malawi
Ghana Coalition for NGOs working in Health	Ghana
Ghana Network of People living wih HIV and AIDS (NAP+)	Ghana
Human Rights Consultative Committee (HRCC)	Malawi
Kenya AIDS Vaccine Initiative (KAVI)	Kenya
Kenya AIDS NGOs Consortium (KANCO)	Kenya
LeGaBiBo - Lesbians, Gays, Bisexuals of Botswana	Botswana
Malawi Economic Justice Network (MEJN)	Malawi
Malawi Health Equity Network	Malawi
Malawi Human Rights Youth Network (MHRYN)	Malawi
Malawi NGO Gender Coordinator Network	Malawi
Malawi Network of Religious Leaders Living with or personally Affected by HIV MANRELA+)	Malawi
Medicine Transparency Alliance (MeTA)	Zambia
National Association of AIDS Service Oranisations (NANASO)	Nigeria
National Association of eople Living with HIV/AIDS (NAPWA)	South Africa
Network of Organizations for Vulnerable and Orphaned Children (NOVOC)	Malawi
Network of Youth Advocates	Nigeria
Network of Zambian People Living with HIV/AIDS (NZP+)	Zambia
Platform of Civil Society Stakehodlers working in Health	Pan African
Regional Network on Equity in Health in East and Southern African (EQUINET)	
SA HIV Prevention Research Expert Group	South Africa
Sex Rights Africa Network	Southern Africa
Southern African Network of AIDS Service Organisations (SANASO)	Southern Africa

NETWORK NAME	AREAS OF OPERATION
Students and Youth Working on Reproductie Health Action Team (SAYWHAT)	Zimbabwe
Treatment Action Literacy Campaign	Zambia
West African NGO Network (WANGONeT)	West Africa
West African Platform for HIV Intervention Research (WAPHIR)	West Africa
Young People's Network on SHR, HIV and AIDS	Zimbabwe
Zambia Interfaith Networking Group on HIV &AIDS (ZINGO)	Zambia
Zimbabwe Association of Church related hospitals	Zimbabwe
Zimbabwe AIDS Network	Zimbabwe
Zimbabwe Young People's Network	Zimbabwe

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