

# SPOTLIGHT SETTING A HIGH BAR FOR ADVOCACY

## Working in Context

The HIV-prevention field is as dynamic as ever. There have been great strides and setbacks since the last issue of *Spotlight* was published in April 2012. At every step of the way, AVAC Fellows have established themselves at the forefront of the action and continue to do so. This issue of *Spotlight* showcases the tremendous headway they've made. For example, in Kenya, Uganda and Zimbabwe, Fellows coalesced to pry open the PEPFAR process to community input, effectively winning allocations for PrEP, TasP and Option B+ targeted to key populations. And in Zambia, it was a Fellow who incentivized Parliamentarians to go for circumcision. While Fellows continue to take up the mantle in East and Southern Africa, AVAC has branched out to Nigeria and China, where there's a need for advocacy inroads.

As always, Fellows work within an ever-evolving arena. Here are some of the prevention field's recent milestones and challenges:

Last July, for the first time, the US FDA approved an ARV (TDF/FTC or Truvada) for use as daily PrEP (pre-exposure prophylaxis) and the WHO administered guidelines for countries to implement PrEP demonstration projects. However, the field is learning

that drug regimen adherence is a bigger hurdle than originally considered. The lesson being, "PrEP works, if you take it."

There's been rapid movement in TasP (treatment as prevention) policy as well, with the WHO poised to recommend ART initiation at a 500 CD4 count. Vaccine research has endured its own peaks and valleys. A herculean research effort determined some possible immune reactions that might have contributed to the vaccine protection seen in the Thai study RV144. Scientists have also begun to understand the body's development of broadly neutralizing antibodies—another potential vaccine advance. On the downside is the recent news that the HVTN 505 vaccine study



Kenya Presidential campaign demonstration, organized by Jacque Wambui, Lucy Ghati and Maureen Milanga



Stacey Hannah, Georgina Caswell and Cai LingPing at Wrap-up & Orientation in Cape Town

*Continued...*

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had to stop injections because there was no signal of protection seen in the vaccinated participants. In the VMMC (voluntary medical male circumcision) realm, there's been a substantial increase in the rate of scale-up, but countries are still behind in achieving their targets.

Also this year, the Global Fund for AIDS, Tuberculosis and Malaria (GFATM) released its New Funding Model and PEPFAR its Blueprint: *Creating an AIDS Free Generation*. Both emphasize continued research and evidence-based combination prevention, two of AVAC's key advocacy goals. Read on for continued Fellows progress and plans for the coming year.

## The 2013ers: Project Profiles

This year's Advocacy Fellows work at the crossroads of research and implementation. Catalyzed by the recent succession of proven interventions, such as TasP and PrEP, the 2013 Fellows are pushing for the integration of ARV-based prevention into National Strategic Plans, for funding targeted to programs for key populations, and for community education and participation every step of the way from research to rollout.

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**Cai Lingping**, China HIV/AIDS Information Network (CHAIN), China

*Project—Creating an enabling environment for PrEP in China*



Cai Lingping

There are PrEP demonstration projects sponsored by China's CDC, but there's also popular resistance to PrEP—namely, concerns that it's targeted to gay men, has side effects, and costs too much. Lingping is working with researchers, gay men, and the government to sway opinion and policy toward a friendlier PrEP environment.

**Josephine Kamarebe**, Health Development Initiative (HDI), Rwanda

*Project—Inclusion of PrEP in Rwanda's national AIDS policy and the monitoring of the rollout of the PrePex device for VMMC.*



Josephine Kamarebe

In the absence of a PrEP demonstration project, Josephine is working with policy makers and community groups to raise awareness and chart a course for PrEP. On the other hand, the country leads the rollout of the PrePex device for non-surgical VMMC. Josephine also plans to monitor the introduction of this device so that other countries might learn from the initiative.

**Rumbidzai (Rumbi) Mapfumo**, The Centre for Sexual Health and HIV/AIDS Research - Zimbabwe (CeSHHAR Zimbabwe), Zimbabwe

*Project—A Call to Action: TasP for Sex Workers*



Rumbi Mapfumo

In Zimbabwe, 60 percent of sex workers are HIV-positive. Getting to zero new infections in the country means no longer neglecting or stigmatizing key populations, including sex workers, so that they can be free to test and get the treatment and care they need. Rumbi is working with health providers to advocate for TasP and for sensitivity to this key population, while also working toward the development of non-discriminatory guidelines.

**Nomonde Mhlali (Mickey) Meji**, Global Network of People Living with HIV (GNP+), South Africa

*Project: TasP and PrEP—The needs of key populations reflected in policy and practice*



Mickey Meji

While South Africa boasts enviable constitutional protections for LGBT people, it doesn't rank high in its just treatment of those living with HIV or sex workers. Within this context, Mickey is working to ensure that national guidelines and policies on TasP and PrEP are developed with feedback from and inclusive of key populations, with an emphasis on MSM (men who have sex with men) and sex workers.

### Coming Up

28–30 May	<i>Women Deliver</i> , Kuala Lumpur, Malaysia
18–21 June	<i>South African AIDS Conference</i> , Durban, South Africa
June 30–July 3	<i>IAS Conference on HIV Pathogenesis, Treatment and Prevention</i> , Kuala Lumpur, Malaysia
June/July	<i>WHO to launch consolidated guidelines to prevent and treat HIV</i>
7–10 October	<i>AIDS Vaccine 2013</i> , Barcelona, Spain
18–20 November	<i>The 2013 Biomedical HIV Prevention Forum</i> , Abuja, Nigeria
1 December	<i>World AIDS Day</i>
7–11 December	<i>ICASA</i> , Durban, South Africa
2013 4th Quarter	<i>AVAC Partners' Forum</i>

**Peter Michira, Partners in Prevention PrEP Thika Study Site, Kenya**



Peter Michira

*Project—Stakeholders' engagement in the adoption of PrEP in Kenya*

Kenya is the frontrunner in Africa's PrEP preparedness. There are several demonstration projects in place and the National Strategic Plan recognizes the need to target key populations in order to realize the goal of zero new infections. Within this context Peter is working with key communities to build PrEP demand and to develop a cohesive plan for the country's PrEP agenda.

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**Maureen Milanga, AIDS Law Project (ALP), Kenya**

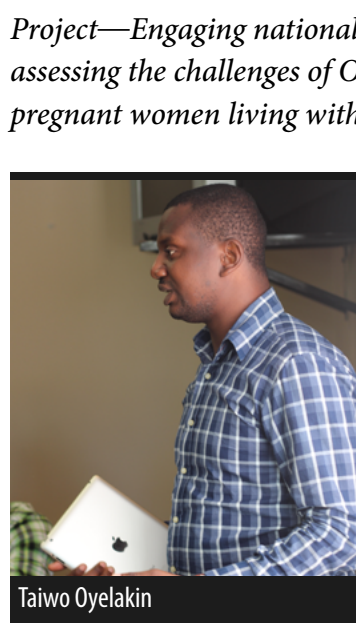
*Project—The policy implementation project: ensuring government guidelines, funding and PEPFAR plans reflect new science*



Maureen Milanga

Standing on the shoulders of her Fellow predecessors, Maureen is working to promote the demands noted in their PLHIV Manifesto (available at [www.avac.org/kenyaPLWHIVmanifesto](http://www.avac.org/kenyaPLWHIVmanifesto)). These include influencing political will and increased PEPFAR and Global Fund allocations to accommodate the updated WHO guideline recommendations to provide HIV treatment as early as 500 CD4 count. She is also monitoring the rollout of Option B+ and advocates for better trade laws around ARV access.

**Oladayo Taiwo Oyelakin, Positive Action for Treatment Access (PATA), Nigeria**



Taiwo Oyelakin

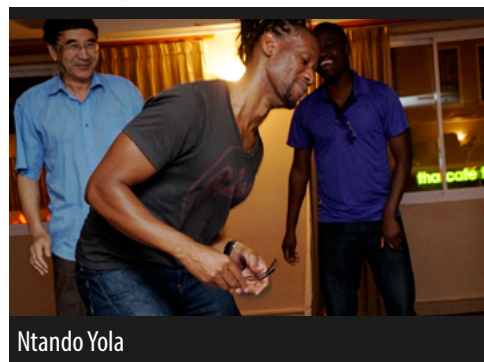
*Project—Engaging national policy makers on TasP and assessing the challenges of Option B+ among young pregnant women living with HIV*

Nigeria has committed to Option B+ but there are gaps in its delivery system. Taiwo is working toward monitoring these breaches with the ultimate goal of strengthening referral systems and linkages to care. He also sits on the National Prevention Technical Working group where he will feed his findings from women's focus groups on Option B+.

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**Ntando Yola, the Networking HIV/AIDS Community of South Africa (NACOSA), South Africa**

*Project—Implementation of GPP to deepen stakeholder engagement in the advancement of HIV prevention research in South Africa*



Ntando Yola

South Africa is an epicenter of HIV prevention research. Ntando is working with the vast constellation of stakeholders from trial participants to bench scientists, ethicists and epidemiologists to develop cohesive national guidelines that would incorporate the key principles in the Good Participatory Guidelines and have buy-in from all those involved. 🌈

# Passing the Baton

## Fellows Wrap-up & Orientation Workshop 2013

The March workshop in Cape Town was a timely opportunity to kick start the incoming 2013 Fellowships. This year's Fellows benefited particularly from veteran Fellows' experiences via formal presentations, lively discussion sessions and hallway chats throughout the three-day meeting. The sharing process demystified the coming year's expectations while setting a high bar for the newcomers.



12ers, 13ers and AVAC staff, tired yet inspired after the Wrap up & Orientation

The agenda also included the requisite sessions: updates on prevention interventions, the research process and advocacy basics; the ever-evolving research-to-rollout landscape; navigation of AVAC's resources; and how to maintain the momentum of the Alumni Fellows. New to the line-up this year was a session on key populations—LGBT, sex workers, IDUs, migrants, and prisoners—to support the majority of new Fellows who are specifically targeting these traditionally marginalized groups within the scope of their projects. A session on advocacy geared toward PEPFAR and the Global Fund was introduced to clarify the processes of community input. 🌈

# Shifting Course

**Both PEPFAR and Global Fund solicit community input**

The world's two largest HIV treatment funders—PEPFAR and the GFATM— have been criticized for a tradition of little community input as to how funding should be allocated in recipient countries. As a result, the ten-year-old US PEPFAR strategy has changed its policy. The 2013 process is the first one to specify that civil society should be engaged in the planning—thanks in no small part to the advocacy coalitions spearheaded by Fellows in Kenya, Uganda and Zimbabwe. Though there's still no perfect or formal roadmap to influencing each Country's Operating Plan, Fellows continue to secure a foot in the door through forged relations, letter writing and sometimes good-old fashioned gatecrashing and bird-dogging. (For AVAC's Advocate's Guide for Influencing PEPFAR Country Operating Plans, go to [www.avac.org/cops](http://www.avac.org/cops).)

The GFATM released its New Funding Model in March. Community input is standardized in this new approach through two essential steps. Each Country Coordinating Mechanism must initiate a "Community Dialogue" where key populations are part of the engagement. During the Community Dialogue, participants prioritize the elements that will go into the application, now known as the "Concept Note." One Fellow has already been invited to help draft a Concept Note. Others might have to elbow their way in a bit, but all are entitled to join the Community Dialogues. 🌈

# 2012ers: Influencing processes and politicians

Last year's Advocacy Fellows made great strides in their respective countries, from bursting open the locked doors of the PEPFAR processes to persuading parliamentarians to go for "the cut," to the doubling of treatment budgets. Speaking for themselves:

**Clever Chilende, TALC, Zambia**

*Project—Advocacy to optimize the benefits of Voluntary Medical Male Circumcision*

### Achievements

- Successfully pressured the Ministry of Health to develop a costed VMMC plan with most of the resources already pledged.
- Led the formation of a VMMC coalition.
- Secured a permanent seat on the VMMC National Technical Working Group.
- Gained civil society access to the Ministry of Finance to influence the health budgets.
- Secured an invitation from the PEPFAR Country Coordinator to be part of its Country Operating Plan process.



Clever Chilende

### Highlight

"The members of parliament offered to be circumcised and arrangements were put in place to do so. At the same time, they promised that they would now take a more strong leadership role in VMMC in their respective constituencies. As a result of this engagement some other members of parliament have since undergone VMMC."

### Now...

Clever is developing a strategic plan for the coalition to broaden its purview beyond VMMC; he continues to engage the Ministry of Finance budget office for increased ownership of the VMMC response; and he is a recipient of a Project ARM Global Lube Access Mobilization advocacy grant.

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**Lucy Ghati, NEPHAK & Jacque Wambui Mwangi, NEPHAK and Health Gap, Kenya**

*Joint Projects—Realizing the potential of TasP & Ending new infections in Kenya in the next five years*

### Joint Achievements

- Developed the PLHIV Manifesto for TasP, informed by the community and taken up by Vice President Kalonzo Musyoka.
- Opened up PEPFAR's Country Operating Plan process to civil society.
- Received a grant for Option B+ awareness from the Elizabeth Glaser Pediatric AIDS Foundation.
- Ensured unspent pipeline money stayed in Kenya to support Option B+ implementation.
- Formed HIV civil society coalition to influence the presidential campaign.

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# 2012 Fellowship Awards

The 2012 Fellows were celebrated at a dinner in March in Cape Town and received special awards. Speaking for themselves...

*The "Acivista"—Power to the People" Award* for creating action within dysfunction goes to Alice Kayongo, unafraid in the face of injustice and who—with a steel will and clear-eyed approach—is able to take on government, bilateral agencies and everyone in between.

*The "Never Gonna Give Up" Award* goes to Bukelwa Sontshatsa for wanting to bring the experiences and realities from the ground to bear on national discussions around TasP and who shined even in the face of setbacks.

*The "Break the Door Down" Award* goes to Chamunorwa Mashoko who refused to be shut out from influencing PEPFAR discussions and who used his reputable DJ skills to spread prevention messages and find a seat at the table for himself and others.

*The "Walk Your Talk" Award* for sticking to strong principles and showing us how it can be done right goes to Clever Chilende who was not afraid to try and try again and who packed a loud punch, even with a quiet demeanor.

*The "Traveling Powerhouse" Award* goes to Jacque Wambui who traveled the length and breadth of Kenya bird-dogging and demanding attention, and whose journey included learning from new challenges and rising from the ashes every time.

*The "Information Is My Power" Award* goes to Lucy Ghati—an image of grace and strength—who smiles while she tells you why the truth and the people behind it will eventually win and who demonstrates that those most affected can be the most powerful in affecting change.

*The "I Will Adapt, I Will Learn, I Will Impress" Award* goes to Lydia Mulwany-Mukombe who was able and willing to take chances, adjust her plans, respond to the needs of the time and excel in all she put her hand to.

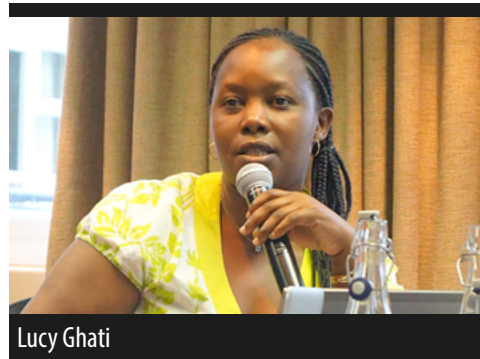
*The "Don't Mess with My Determination" Award* goes to Memory Makamba who you may not always hear, but whose powerful and determined advocacy you will feel—as it quietly changes minds and forces the powers that be to reckon with evidence. 🌈



Memory, Chamu, Clever, Lucy, Alice and Jacqueline basking in their glory

**Highlight**

“During World AIDS Day we were showcasing what we had done over the year and when Vice President Kalonzo



Lucy Ghati

Musyoka came to the NEPHAK stand he got so interested with the explanation I gave about the PLHIV Manifesto, he picked it and promised to incorporate the demands in it onto his party's manifesto.”

“The day we were addressed directly by the Deputy



Jacque Wambui

Prime Minister Mu-salia Mudavadi during a campaign rally. Towards the end of his speech after noticing our placards he addressed us saying that his party would ensure that all Kenyans would get access to healthcare for a healthy society, which will lead to a

healthier economy.”

**Now...**

Lucy serves on the Program Advisory Committee that is spearheaded by NASCOP and FHI 360 to continue championing the HIV prevention research agenda. She is also on the steering committee for the Global Plan Toward Elimination of Vertical Transmission of HIV.

Jacque helps Kenya's 2013 Fellow push the Manifesto forward until all its demands are met.

**When vice president Kalonzo Musyoka came to the NEPHAK stand he got so interested with the explanation I gave about the PLHIV Manifesto, he picked it and promised to incorporate the demands in it onto his party's manifesto.**

**Alice Kayongo Mutebi, International HIV/AIDS Alliance Uganda, Uganda**

**Project—Advocating for Treatment as Prevention in Uganda Project**

**Achievements**

- Built on and sustained former Fellows' HIV Prevention Coalition in Uganda.
- Influenced the revision of Uganda's PEPFAR Country Operating Plan to double its treatment targets, implement Option B+ with the hiring of 800,000 midwives and scale up access to CD4 tests.
- Critiqued and responded to the 2011 Uganda AIDS Indicator Survey.



Alice Kayongo

**Highlight**

“My experience having participated in the 2012 Joint Annual AIDS Review and Partners Forum was a major highlight! Particularly, sharing of the 10-point plan to end HIV/AIDS in Uganda and seeing the [PLHIV] community confidently challenging the Uganda AIDS Commission (with a lot of insights from my work) were major highlights!”

**Now...**

In her new position as Manager of Policy and Advocacy at the International HIV/AIDS Alliance in Uganda, Alice continues follow-up with Uganda AIDS Commission to ensure the implementation of the AIDE MEMOIRE, to influence PEPFAR and the national health budget and to lobby for treatment scale-up.

**Memory Makamba, ZAPP-UZ, Zimbabwe,**

**Project—HIV prevention for serodiscordant couples**

**Achievements**

- Helped influence policy to integrate serodiscordant couples into HIV Testing Strategy 2012-2015.
- Engaged with PEPFAR process, securing US\$38 million in additional funding for PMTCT, VMMC and TasP.
- Educated communities on the importance of TasP.

**Highlights**

“Attending the World AIDS Day pre-launch activity that was organized by the Zimbabwe National Network of PLWH



Memory Makamba

(ZNNP+) was the major highlight for the fellowship. Listening to the people that we purport to represent gave a human face to the work that I have been doing.”

**Now...**

Memory has received a new appointment—a post created specifically for her at her host organization, CeSHHAR.

**Chamunorwa Mashoko, University of Zimbabwe-University of San Francisco Research Programme, Zimbabwe**

**Project—Combination HIV Prevention Revolution**

**Achievements**

- Established the Zimbabwe HIV Advocacy Coalition.
- Participated in the development of the National Combination HIV Prevention Strategy.
- Together with the Coalition advocated for involvement of civil society in the development of PEPFAR Country Operating Plan. Zimbabwe was awarded US\$39 million in additional funding.
- Created “For You I Will”, the combination HIV prevention song currently on air in Zimbabwe.



Chamu Mashoko

**Highlights**

“Raising the Zimbabwean HIV funding issue to Ambassador Eric Goosby [US Global AIDS Coordinator and head of PEPFAR] in Canada at the International HIV TasP Workshop in Vancouver.”

**Now...**

Chamu pushes for increased domestic HIV funding in Zimbabwe where 70 percent of HIV funding is from external donors. He also ensures that coalition activities are maintained, identifying and training more advocates.

*Continued*

## 2012ers (continued)

Lydia Mulwany-Mukombe, ICW East Africa, Uganda

*Project—Understanding what HIV prevention research results mean for women*

***I gathered stakeholders' views on hormonal contraceptives and HIV risk...contributing to the development of global guidance documents.***

### Achievements

- Influenced WHO technical statement and global processes to be more transparent around hormonal contraceptive and HIV risk.
- Documented women's views on PrEP in Kampala and Mubende districts, held advocates meetings on PrEP and drew a timeline for PrEP advocacy.

### Highlights

“The fact that I gathered stakeholders' views on hormonal contraceptives and HIV risk, which were then presented in subsequent WHO meetings, hence contributing to the development of global guidance documents.”



Lydia Mulwany-Mukombe

### Now...

Lydia builds on her work in 2012, strengthening the advocacy coalition for family planning in Uganda, with a specific focus on increasing access to a variety of family planning methods.

Bukelwa Sontshatsha, World AIDS Campaign International, South Africa

*Project—Assessing the views of PLHIV to be included for policy consideration*

### Achievements

- Educated communities on TasP.
- Developed advocacy groups in the Eastern and Western Capes to move forward the TasP agenda.

### Highlights

“Educating the communities and showing what's in [TasP] for them.”

### Now...

Working with the Emavundleni Prevention Centre as a CAB member and through this link serving in the ASPIRE Community Working Group of Microbicides Trials Network and as a CAB representative in the HVTN 506 protocol team.



Bukelwa Sontshatsha



[www.avac.org/spotlight](http://www.avac.org/spotlight)

# Partners' Forum Highlights

In December last year, AVAC gathered more than many of its partners in Johannesburg for its yearly meeting. The AVAC 2012 Advocacy Partners' Forum: Advocacy to begin to end AIDS was an opportunity to connect, build skills and prioritize activities for the following year.

The meeting culminated in an advocacy plan for 2013 activities and goals for Sub-Saharan Africa, including but not limited to:

- Combination prevention: Governments define and justify their combination prevention packages.
- PrEP: A clear set of PrEP demonstration projects and guidelines, and Truvada (TDF/FTC) access for post-trial participants.
- TasP: Scale-up of treatment now, ensuring TasP availability on demand.
- VMMC: Amplified demand and preparation for new devices in all 14 priority countries.
- Hormonal contraceptive and HIV risk: more research, clear guidance and communication.
- Vaccines: Continued community preparedness for South Africa's clinical study, building on the success of the Thai trial; and support for other HIV vaccine candidates slated for discovery trials.
- Microbicides: Prepare for tenofovir gel results, while ensuring research pipeline.
- Key populations: Address rights of key populations (gay men and other MSM, sex workers, injecting drug users, migrants and prisoners) and structural issues as part of combination prevention.
- GFATM, PEPFAR and WHO: Global leadership and ongoing financial support. 🌍



Forum participants...

## The GLAMorous Side Meeting: Improve Lube Access in Africa with the new GLAM Toolkit

AVAC, amfAR and IRMA's Project ARM (Africa for Rectal Microbicides) organized a post-Partners' Forum meeting to launch the new GLAM Toolkit (available at [www.avac.org/glamtoolkit](http://www.avac.org/glamtoolkit)). The document is a guide to lubricant access and anal sexual health advocacy. Though most of the AVAC partners joining the GLAM (Global Lube Access Mobilization) meeting were first-timers, many brought informed perspectives on the challenges of lube advocacy. These include: the need for more research to determine the safest lubricants; how to message for lube access while not having all the safety data; and the need to facilitate anal sexual health advocacy and messaging. Several of the AVAC partners signed on to Project ARM and one—Clever Chilende—was even awarded a GLAM advocacy grant. 🌍





## Call for Applications for 2014 AVAC Advocacy Fellowships

*Have you been working in the HIV/AIDS or related field for a few years and looking for an opportunity to build your advocacy skills in the exciting world of HIV prevention research and implementation?*

*Is your organisation looking to get more involved in HIV prevention research and implementation advocacy? Is your organisation considering hosting an AVAC Advocacy Fellow in 2014?*

### **APPLICATIONS NOW BEING ACCEPTED!**

There will be an information call on June 26, 2013. Find details and download application materials at [avac.org/2014fellowsapps](http://avac.org/2014fellowsapps).

Questions? Write to [fellows@avac.org](mailto:fellows@avac.org).

**Deadline - MONDAY August 5, 2013**

### **About AVAC**

Founded in 1995, AVAC is a non-profit organization that uses education, policy analysis, advocacy and a network of global collaborations to accelerate the ethical development and global delivery of AIDS vaccines, male circumcision, microbicides, PrEP and other emerging HIV prevention options as part of a comprehensive response to the pandemic.

## About the Advocacy Fellowship

The HIV Prevention Advocacy Fellowship pairs emerging leaders in advocacy and activism with existing organizations to develop and execute creative, context-specific projects focused on HIV prevention research and implementation.

Fellowship projects focus primarily on advocacy around biomedical HIV prevention research (such as clinical trials of vaccines and microbicides) or rollout of male circumcision for HIV prevention, ARV treatment as prevention strategies and pre-exposure prophylaxis.

The Fellowship is a program for emerging and mid-career advocates in developing countries interested in effecting change on issues related to biomedical HIV prevention research and implementation. It is designed to strengthen the capacity of individuals and organisations interested in working in this area. The program provides financial and technical support for selected Advocacy Fellows.

The 2013 Fellows are currently implementing their advocacy projects. To learn more about their projects, please visit [www.avac.org/fellows](http://www.avac.org/fellows).

