

An enriching immersion into HIV prevention advocacy



Voices of self-doubt

My acceptance into the AVAC Fellows Program in 2015 was a dream come true. I knew that the journey ahead would be both exciting and challenging and that it would provide a perfect opportunity to channel my passion for supporting research and innovation for biomedical HIV prevention tools- the work, I have been doing for over two decades. In the midst of my excitement, small voices in my head started asking several questions and among them was ‘Do you really have the capacity needed to get started and succeed in this program?’ This debate with myself continued almost to a point of discouragement. Eventually, the voices of self-doubt were muted by recalling Mahatma Gandhi’s inspirational quote which says, “If I have the belief that I can do it, I shall surely acquire the capacity to do it even if I may not have it at the beginning” The Fellows program became the vehicle I needed to take me to my long-desired destination- to be an accomplished advocate, and I am so delighted to announce my arrival.

AVAC Fellows Program

The AVAC Fellows Program 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 of new prevention interventions. It provides experiential learning as well as organized professional development, coaching and mentoring.

The Aim of the Project

My Fellowship project, focused on pushing for access to pre-exposure prophylaxis(PrEP), and the development of extended PrEP guidelines that include all people at substantial risk of HIV infection in South Africa. In the process, I also worked closely with other PrEP advocates, civil society and clinical trialists to prepare for the results of the microbicide vaginal ring trials, ASPIRE and the Ring Study.

Oral PrEP is an exciting addition to the HIV prevention toolbox that involves HIV-negative people at substantial risk of infection taking a combination antiretroviral drug (TDF/FTC) as part of a proven, comprehensive HIV prevention approach.

Project Goals

The project centred on three main objectives namely;

- 1) Work with decision-makers in the National Department of Health (NDoH) to accelerate the process of developing extended PrEP guidelines,
- 2) Civil society advocacy and demand for policies for PrEP implementation and
- 3) Effectively engage and support civil society and clinical trialists in preparing for the results of the microbicide vaginal ring study.

The context matters

Understanding the context of a project is critical to its successful implementation. With this in view, I conducted in-depth interviews, with key informants to gain an understanding of ; the key players in PrEP advocacy in South Africa, dialogue around PrEP, stakeholder involvement in the development of PrEP guidelines for men who have sex with men (MSM), the status of plans to develop extended PrEP guidelines, the status of the application to have Truvada approved for PrEP and what needed to be done to speed up the process, issues regarding PrEP that communities needed to know about, what needed to be done to prepare for PrEP rollout and how best advocates and civil society could help push the PrEP advocacy agenda forward. This data informed the development of a comprehensive work plan, advocacy strategies and the building of a strong coalition.

Advocacy Strategies

Multiple advocacy strategies and platforms were used to achieve the goals of this project. These included meetings, conferences and community dialogues to get people talking about PrEP and build support for the campaign. Blogs, opinion editorials, press statements and radio interviews were also used to influence decision makers, share thoughts and opinions on how PrEP could be rolled out and how advocates could support the rollout process.

Key Project Accomplishments

Successes scored during the period of the Fellowship were amazing.

- The Medicines Control Council approved the use of Truvada for PrEP on 27 November 2015.
- National Oral PrEP and Test and Treat guidelines and an accompanying policy have been drafted and are near finalization.
- Plans to rollout PrEP to sex workers as well as providing HIV treatment to those who test positive are underway and advocacy to ensure that PrEP is made available soon to all those who need it continues unabated.
- In anticipation of the vaginal microbicides ring results, elaborate preparations were made. The International Partnership for Microbicides (the developer of the vaginal ring technology) and the Microbicides Trials Network convened partners meetings to plan for possible result scenarios, while PrEP advocates conducted discussion forums with civil society to brainstorm on the way forward following the announcement of the results. In the process of preparing for these results, the AVAC mentors provided critical advice and guidance. The study results were a remarkable achievement in microbicides research and as advocates we are pushing for the immediate dissemination of these results and supporting actions to speed up the process of making the microbicide vaginal ring available as an additional HIV prevention option for women.

Challenges encountered

Lailah Gifty Akita says “There are no smooth paths to success. You have to straighten many rugged roads and scale numerous walls for the ultimate triumph”. This was true with my Fellowship experience. During the initiation phase of my project, I had problems getting accepted by some advocates and stakeholders who were already involved in PrEP advocacy in South Africa. This was a painful experience as I would sometimes be side-lined or simply ignored when I tried to foster collaboration. The AVAC mentors had to intervene to rectify this situation and to some extent, their efforts were positively rewarded. Even though a spirit of collaboration was engendered among us, proper coordination of our advocacy efforts lacked and again, this was quickly noted by the mentors, who then encouraged me to take on a leadership role and help drive the advocacy efforts forward.

I also had to contend with some stakeholders whom I really wanted to meet to discuss ways we could work together and support each other’s efforts, but regardless of my persistence to set up meetings with them, they were either unresponsive or kept on dishonouring the appointments. These included two senior authorities from the National Department of Health and staff from some big research institutions. On the advice of my mentors, I resorted to using other advocacy strategies like blogging and I took the lead in writing an opinion editorial that made a great impact.

As I look back and reflect on these challenges, I hardly believe that after being disregarded, I am now being invited by the Department of Health representatives to participate in meetings to plan for PrEP implementation. As advocates, we should learn to embrace challenges as they enable us to realize our untapped potential. Ray A. Davis sums this up quite nicely by pointing out that “A challenge only becomes an obstacle if you bow to it”.

Professional and Personal Growth

The Fellows program was a mind-opening and life-changing experience. It expanded my skills set and provided me with an enriching immersion into HIV prevention advocacy work and an opportunity to enhance the grassroots component of the work of my Host organization, TB/HIV Care. At the commencement of the Fellowship, my mentors impressed on me the importance of collaborative advocacy. I was not quite sure how this would work but with their support and encouragement, I managed to work collaboratively throughout the Fellowship year with former AVAC advocacy Fellows, civil society organizations, advocacy champions and other influential individuals who played a key role in advancing the advocacy agenda. This experiential learning has really helped me to master the art of collaborative working. To boost my leadership skills, the AVAC mentors urged me to take leadership tasks especially in situations where I felt challenged. In this process, I learnt how to inspire others, build consensus and work out of my comfort zone especially since advocacy work can be very demanding and stressful at times. Learning how to multi-task and manage my time through organization, prioritizing and scheduling my day was also a very good learning experience that helped me to achieve much in a limited period of time.

Since communication is at the heart of advocacy implementation, I have emerged from the Fellowship programme, better equipped to use different types of communication medium to get across important messages to people. These include large meetings, conferences, emails, text messaging, meeting minutes and social media.

It also feels so good to know that I can now write blogs and opinion editorials that enable me to share my thoughts and opinions, build rapport and engagement with other advocates and help build coordinated efforts towards supporting the development of new interventions needed to end the AIDS epidemic. Through writing numerous project reports, developing advocacy informational

materials such as factsheets, posters and petitions, reviewing and editing documents, my writing skills have greatly improved and my interest in writing for publication has been re-ignited.

At certain times during my Fellowship, my confidence would be challenged when undertaking unfamiliar tasks, even so, my mentors and host supervisor were very helpful in building and restoring my confidence and I now work well in challenging settings.

Self-awareness

In the process of doing advocacy work, taking stock of one-self is key to self-improvement. The Fellowship has allowed me to gain a deeper understanding of my strengths and challenges. For instance, I have learned that I am results-driven and I have strong people skills but at times, I tend to underestimate my ability. For instance, I am hesitant to break new ground but once I start working on a task, there is no turning back. Apart from unravelling my hidden potential, the Fellowship has also acted as a catalyst for change in my personality. Naturally, I have a passive personality but now I realize I have become more assertive in order to get things done.

AVAC's mentorship program from a mentee's perspective

Mentorship was a critical component of the Fellowship program. Prior to the commencement of the Fellowship, I had wondered how long-distance mentoring was going to take place from a distance. Now, I realized that this was possible through constant email communication, Skype, teleconference calls, and other types of social media communication and on-site visits. Monthly supervision calls with the mentors, were also key to the capacity building process. Through these calls, I was given the opportunity to reflect on what I had learnt- the progress made, the challenges encountered and the opportunities that I could take advantage of. Our discussions during these calls kept me focused on my goals and more importantly, I got technical assistance on the projects I was working on. The mentors also acted as a sounding board of my ideas and I found this very helpful.

In fact, I need to mention that I was blessed with some great mentors who were very supportive, well experience, smart, always available for me and they demonstrated that they had my best interest at heart.

The Host organization

There is no way that my Fellowship would have gone as smoothly as it did without the support of my host organization, TB/HIV Care. I enjoyed every moment of being part of a team that is passionate about providing integrated TB and HIV health care services to communities. My work on PrEP advocacy and the contributions I made to the organization were acknowledged and posted on the organization's website and social media sites. In terms of support, I had access to the resources and tools I need to do my work, and special care was taken to ensure that I was well supported by staff from other relevant departments within the organization. Personnel from the Human Resources and Finance departments as well as the Chief Executive Officer, Professor Harry Hausler, made sure that I was invited to the organization's social events as a way of enhancing social bonding with other staff members.

Lessons Learned

Project planning

Upon reflecting on my project accomplishments, I have come to appreciate the importance of thorough planning. This involved being taken through an elaborate orientation and a step-by-step process of developing strategic plans using carefully designed templates as planning tools,

consultations with stakeholders and the use of data gathered from the landscaping exercise mentioned above.

Project Implementation

To successfully implement an advocacy campaign, support from relevant stakeholders is required. I have therefore learned the necessity of associating with influential individuals, advocates, champions and credible organizations. These help to create a way where there seems to be none. For example, connecting with the South African National AIDS Council Women's Sector, authorities in the National Department of Health and other institutions was not easy, I had to seek the assistance of my mentors, local advocates and influential individuals and this worked out well.

Fellow Supervision

Given the importance of supervision calls and meetings as mentioned above, I have learned that it is important to be adequately prepared for these meetings and take full advantage of this opportunity to seek guidance. I therefore recommend that discussions during these meetings be documented for reference purposes.

Seizing Opportunities

When doing advocacy work, I have also learned that there are some special advocacy moments that one needs to take advantage of in order to bring an issue to the public arena and attract attention and support for it. I had to watch out for these moments and in addition, my mentors also encouraged me to attend meetings and conferences which also made the program very interesting and enriching. The 7th South African AIDS Conference, held 9-12 June, 2015 presented a great moment and a turning point in PrEP advocacy in South Africa as this provided an opportunity for advocates and potential users of PrEP to make their voices heard and demonstrate that their demands would continue until the request to make PrEP available in the country was met.

Tips for successful advocacy work

In order to successfully advocate for a cause, there are a number of things that should be taken into consideration. Below are a few tips for successful advocacy work;

- Select the advocacy issue carefully,
- Gain a clear understanding of the social, political and policy contexts of the project,
- Build evidence to support the advocacy issue,
- Identify and engage stakeholders and advocacy champions,
- Use multiple advocacy strategies and platforms,
- Put an effective coordination structure in place,
- Take advantage of special advocacy moments,
- Press on and keep focused on the advocacy goals,
- Take supervision by both Fellows Program mentors and Host supervisors seriously,
- Engage in cycles of action and reflection at every stage of your advocacy project.

Beyond the Fellowship

Making the best use of the knowledge, skills and experience gained from the Fellowship training is important to advancing the domain of HIV prevention advocacy. My plans for the immediate future are to continue writing advocacy pieces and working together with other HIV prevention advocates to

lead or support in-country advocacy efforts and engage in international advocacy initiatives. To continue nourishing my passion for working with communities, I would also like to participate actively in building advocacy capacity at this level through facilitating community trainings and providing advice and guidance where needed. I would also like to participate in mentoring other budding advocates as a way of supporting and sustaining AVAC's capacity building efforts.

Thumbs up to AVAC and TB/HIV Care, I wish I could turn back the hands of time and re-live the experiences of the AVAC Fellowship program.