

STORY OF CHANGE: KENYA

The Best Treatment for Women Living with HIV: Access to Dolutegravir for Adolescent Girls and Young Women

The problem

Dolutegravir (DtG) is an antiretroviral (ART) that was approved for use in Kenya in February 2018 as an alternative regimen for HIV patients who exhibited intolerance to Efavirenz (an alternative ART also available in Kenya), injected other drugs while on antiretroviral therapy, or were unresponsive to second line ARV drugs. DtG has a good resistance profile and minimal side effects, and those using it are able to achieve viral suppression faster than those using Efavirenz. Because of these characteristics, DtG was welcomed by people living with HIV in Kenya and preferred over Efavirenz, which had been used as the first line of treatment in Kenya before DtG was introduced. However, in June 2018 the World Health Organization (WHO) advised against the use of DtG for adolescent girls and young women of reproductive age, after a study from Botswana showed that it may cause neural tube defects (NTD) at conception or during early pregnancy¹.

By the time WHO issued this warning, Kenya had already started administering DtG to women living with HIV. The country subsequently withdrew the use of DtG for women of reproductive age (15-49). Communities of women living with HIV in Kenya were highly concerned that they had not been consulted on this decision, which would fundamentally affect their right to choose their treatment options (regardless of their age) and their ability to make decisions regarding their reproductive lives.

The change process

In June 2018 communities of Women Living with HIV (WLHIV) came together from different organizations and raised concerns to the National AIDS & STI Control Programme (NASCO) on the issue of access to DtG for women of reproductive age. However, soon it was clear that these attempts were unsuccessful.

In July 2018, AfroCAB—a network of community HIV treatment advocates across Africa—mobilized thirty women from different African countries to attend the Stakeholder Meeting of African Women Living with HIV in Kigali (13–14 July, 2018), to deliver a statement of their demands with respect of access to DtG². PITCH partner, NEPHAK (Kenyan Network of People Living with HIV and AIDS) joined AfroCAB at the Kigali meeting, along with other organizations from Kenya including PITCH's partner organization, the Ambassadors for Youth and Adolescents Reproductive Health Programme (AYARHEP). They were also joined by other PITCH partners from Zimbabwe and Uganda. One of the demands put forward by the coalition was that they wanted to be involved when decisions affecting WLHIV are being made.

¹ <https://www.aidsmap.com/news/jul-2019/dolutegravir-safety-pregnancy-risk-lower-first-reported>

² <http://www.afrocab.info/meetings/past-meetings/>

During the 2018 AIDS Conference (23–27 July, 2018) in the Netherlands, PITCH partners AYARHEP, Kenya Sex Worker Alliance (KESWA), and Bar Hostess Empowerment and Support Program (BHESP) joined a protest of WLHIV at a WHO-organized meeting on guidelines for HIV treatment. The messages presented included:

- “We want DtG for all now”
- “Stop discriminating against women”
- “Do not deny us, WLHIV, access to DtG regardless of our childbearing potential”
- “Strengthen HIV and SRH services to ensure access to DtG together with acceptable, available, affordable, and accessible contraception”
- “Do not force WLHIV to take a particular medication”
- “Clearly communicate the short- and long-term side effects of ARVs to enable us to make informed decisions”
- “Involve us, the WLHIV, in local, national, and global discussions and decisions regarding HIV treatment options”

Upon return to Kenya, in August 2018, NEPHAK started strategizing and implementing an advocacy campaign, directing its efforts towards the NASCOP of the Kenya Ministry of Health (MoH) as the main advocacy target. NEPHAK was joined by its members, PITCH partners AYARHEP, Y-Plus Kenya, Women Fighting AIDS in Kenya (WOFAK), LVCT Health, BHESP and KESWA) and other CSOs (e.g. the SRHR alliance). KESWA was involved in the planning and execution of the advocacy campaign; AYARHEP, Y-Plus Kenya, and WOFAK contributed to the mobilization of young women and girls living with HIV/AIDS at the community level, and BHESP was involved in the mobilization of young sex workers. LVCT Health engaged with women in hospitals and treatment centres and was involved in lobbying at the level of the National Technical Working Group and GFATM. KELIN supported the campaign by helping AYARHEP in drafting a petition directed at NASCOP, the MoH, and WHO.



Towards the end of 2018 and after receiving training on community dialogue from AfroCAB, PITCH partners in Kenya organized meetings with women and girls and CSOs on a community level to discuss their fears regarding DtG. They also brought in medical experts to respond to these fears by providing information. Through this community dialogue, a broad range of girls and young women (including

female sex workers) were informed and empowered to engage in the advocacy. Funded by PITCH, AYARHEP worked to strengthen the capacity of adolescent girls and young women to advocate for increased access to equitable and rights-based HIV treatment in order to enhance their meaningful engagement. AYARHEP conducted a survey among adolescent girls and young people on their perceptions of DtG and used the results to mobilize public support by sharing key messages on the need for the government to reinstate DtG guidelines and conduct sensitization meetings with stakeholders on the reinstatement. Other partners working at the community level were also able to generate evidence and mobilise adolescent girls and young women within the communities to gather evidence for the national DtG advocacy campaign. PITCH enabled them to cover the costs for young people to attend these meetings. Moreover, WOFAK, partnering with other women led CSOs like Young Women Against AIDS (YWAA), utilized county stakeholder forums to advocate for a DtG regimen for all adolescent girls and young women with HIV and other SRHR issues, under the slogan *every woman every child counts*.

PITCH partners likewise were actively engaged in online campaigns, mainly through Twitter, and were able to mobilize a lot of online discussion. Over the course of these social media campaigns, a clear message emerged that women want choice and to be able to decide about their medication and reproductive lives for themselves. Journalists were also engaged to make the campaign visible and to convey correct information related to DtG more broadly.

On 10 April, 2019, with support of PITCH Funds, a peaceful march was organized by AYARHEP, WOFAK, BSHEP, KESWA, and Y+ Kenya demanding that the directive prohibiting the use of DtG by women of childbearing age be rescinded by the Ministry of Health. For this purpose, a petition covering the below issues was developed:

- Revise the cautionary measures that were barring women from access to DtG;
- Withdraw the consent form that women had to sign to access DtG;
- Revise the clinical guidelines on working with DtG at the community level and at health facility level;
- Provide HIV treatment literacy in all the forty-seven counties for women to understand their treatment well.

NASCOP agreed to address the demands presented in the organizations' petition (see above), starting with a revision of the caution on the use of DtG.

In parallel with this process, in July 2019 at a conference in Mexico, WHO lifted the caution/advisory on the use of DtG after additional research from Botswana found that the risk of NTDs was less than originally suspected. The communication from WHO was followed by consultations between the Kenyan Ministry of Health and other key stakeholders, including WLHIV and civil society organisations. Updated guidance was subsequently issued by the Kenyan Ministry of Health on 25 July 2019. The new guidance was sent to all concerned parties across Kenya's forty-seven counties, namely: County Executive Committee Members of Health; County Chief Officers of Health; County Commissioners; and County AIDS and STI Coordinators.

On 9 August, 2019, in a follow-up to the Ministry of Health, NASCOP updated its guidelines on DtG, sending a notification to facilities which lifted the restrictions and allowed consenting women of a child-bearing age to be given DtG as a first line of treatment.

Lessons learned

The success of the DtG campaign in Kenya shows above all that unity is strength. By engaging in the campaign jointly, the different organisations (including PITCH partners) were able to amplify their

voices. In particular, the empowerment and strong engagement of the community in the process was a success factor in the campaign. Young people not only actively engaged in evidence generation and important activities like the march but also played a key role in the social media campaign—which made the advocacy particularly powerful. Finally, the advocacy work around DtG raised a number of issues that partners had not been taking as much interest in previously, such as the diagnostic care of young people living with HIV, aspects of early infant diagnostics, kidney tests, and liver tests, to show that the welfare of the patients is being upheld. The advocacy also created a ripple effect for issues affecting other people living with HIV. The other lesson was had Kenyan civil society and communities not organised themselves and lobbied the Kenyan MoH/NASCOP, then when the WHO changed their guidance in July 2019, in response the MoH may not have actively consulted Kenyan civil society.

The story was prepared as part of the End Term Evaluation of the PITCH Programme in 2020, conducted by ResultsInHealth team: Aryanti Radyowijati, Conny Hoitink, Zaïre van Arkel, Maurizia Mezza, Lingga Tri Utama, and Awuor Ponge (national consultant).

