ADDRESSING THE ELEPHANT IN THE ROOM: STIGMA AND PrEP ROLLOUT

PrEP Learning Network Webinar Series

Thank you to our speakers, Laura Nyblade, from RTI International, and Elizabeth Irungu, from Jomo Kenyatta University, as well as attendees who participated in the thirteenth PrEP Learning Network webinar. In this webinar, we heard from Laura on lessons learned on reducing stigma in health facilities in Ghana, Tanzania, and Thailand and from Elizabeth on Kenya's approach to 'PrEP for all'. A public-service announcement geared toward combatting PrEP stigma in South Africa was also shared from Wits RHI. In case you missed it, you can access the webinar recording here.

Top 8 Questions

Many questions were raised during the webinar's Q&A, and summaries for the top eight are provided below. Learn more by listening to the webinar recording, accessing complementary resources, signing up for future webinars, or visiting the PrEP Virtual Learning Network page.

1. **How can key populations be engaged within the training?**

   In other stigma and discrimination trainings a "living library" is included whereby community representatives share their experiences in healthcare settings so that health care providers can learn directly by those affected by stigma in the health facility. In other models the training itself is led by individuals who are part of the stigmatized groups. It's important to recognize that, particularly in countries where key populations are illegally as well as socially stigmatized, these populations may not feel comfortable fully engaging for structural reasons.
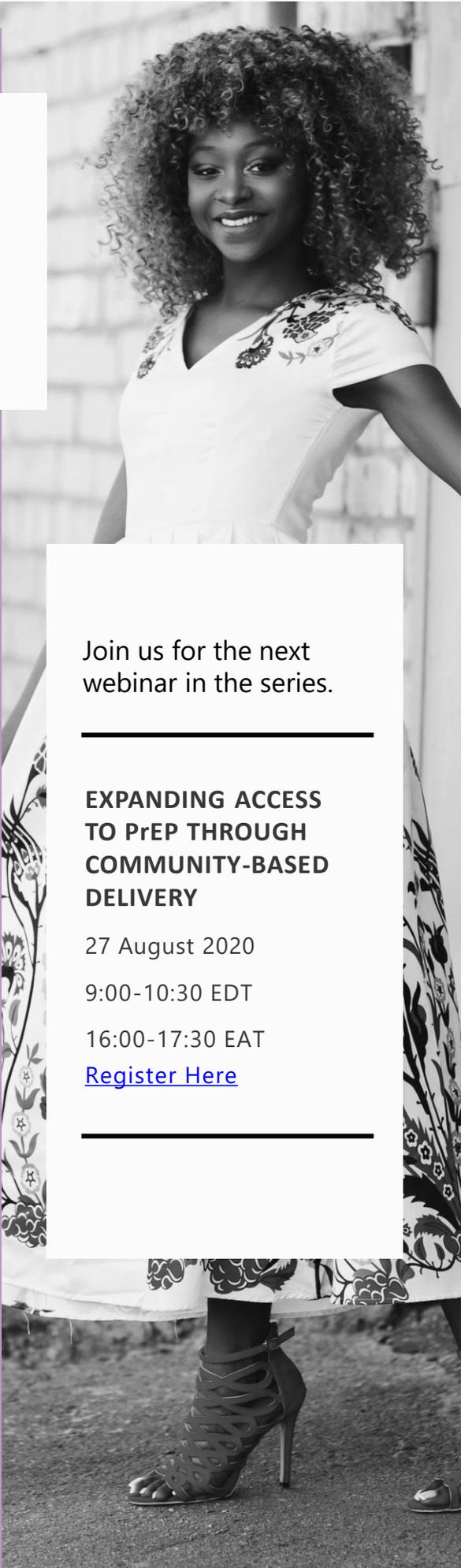
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Top 8 Questions (continued)

Within this context, to ensure engagement is conducted safely, there may be an opportunity for video or audio clips to be made of individuals (key populations) and anonymized to allow for virtual involvement. Involving stigmatized populations could also include working through networks to design questionnaires as well as tool adaptations. As a part of RTI's Health Policy Plus project (HP+) training in Ghana and Tanzania, health facility workers are paired with clients (people living with HIV, key populations, adolescents) and trained together as stigma-reduction facilitators who then conduct the participatory training of health workers. In addition, the 2-day modular training curriculum (which can be delivered flexibly, for example across multiple afternoons) includes a panel of members of stigmatized groups (can include people living with HIV, sex workers, and men who have sex with men) as well. Criminalization of activities that heighten HIV risk adds to the challenges of working together with key populations but the more space that is provided for safe spaces for contact and learning between the stigmatizer and the stigmatized the more this stigma will start breaking down.

2. **How do you ensure that clinical staff do not "lead" the conversations during the training?**

One of the features of the HP+ stigma-reduction training is that all levels of staff (clinical and non-clinical) are trained together. Given the potential power dynamics when mixing levels of staff, the skills of the stigma-reduction facilitators (trainers) are key, which is linked to their training. In the HP+ approach, as noted above, health care staff and clients are trained as stigma-reduction facilitators (five days of offsite training plus five days of 'on-the-job' coaching) as they roll out the first stigma-reduction training to health facility staff. In addition to learning how to handle potential difficult group dynamics with the mix of levels of staff, the stigma-reduction facilitators are trained to ensure they create the safe environment that allows participants to explore their own perceptions and are not influenced by trainer attitudes and beliefs. An example from the training provides a practical activity for addressing the power dynamics that may occur when mixing clinical and non-clinical staff in the same training: Everyone is provided with a paper hat and each participant (or trainer) writes down all of their roles/associations on the hat – sister, health provider, supervisor, mother, etc. There is a discussion about how we identify ourselves and others, and all the different identities we hold. Hats then go in the corner, and people leave them behind (disassociate from these roles) during the training. Everyone engages on the same level throughout the training and then pick up their hats on the way home/end of the day.

Top 8 Questions (continued)

3. Do you have lessons for reducing stigma in community services?

The HP+ project does not have specific examples for community services, however the approach shared can be easily adapted to different kinds of services. The basic principles apply across all modes of service delivery and the participatory training tools are easily adapted. The key is understanding what the actionable drivers of stigma are in a particular context and/or target group.

4. Have you engaged parents or care givers to empower them with information so that they are open-minded in supporting and talking to young girls about taking up PrEP?

Parents and care givers are key to supporting and encouraging young people. RTI, with NIH funding, is in the process of testing a multi-level intervention that focuses on adolescent girls and young women, parents and care givers and clinics around HIV prevention services more broadly, including PrEP. While there isn't a specific example to share at this time, the participatory stigma-reduction training tools developed originally by the International Center for Research on Women and the Academy for Educational Development to be widely adaptable for different target groups, and that have since been adapted by the HP+ project specifically for the health facility setting, could be easily adapted to focus on parents and caregivers. What will be key is understanding where the parents and caregivers are 'coming from' – what are they afraid of (e.g. what will my neighbors say about us if we support our daughter to use PrEP?, how will this affect future fertility of my child?) – and then tailoring the intervention to address these specific concerns.

5. How can self-stigma be addressed?

Internalized stigma is an important type of stigma to be addressed, and a challenge. Most of the internalized stigma reduction examples come from the global north, however the principles translate. Networks or other forms of support groups are key. RTI, in partnership with Duke University, is currently adapting and testing a successful video/story-based internalized stigma-reduction intervention for women living with HIV in the Southern US, to address internalized stigma for women living with HIV in Tanzania. This work is ongoing. Building support and solidarity through networks and other forms of support groups, building self-esteem and skills to challenge stigma when it happens, and strengthening livelihoods/employment, can all help reduce self-stigma.

It is important to acknowledge that it is possible to address stigma. The LINKAGES experience with addressing stigma and discrimination was shared. This program also has a training curriculum called Health for All (see resources below) to build provider capacity, address stigma and establish empathy. Again, this training experience reinforced that bringing key populations into the training to have dialogue with health care providers is incredibly important and transformative for the providers.

6. **How successful do you think you have been in addressing stigma, and what remains to be done?**

Early messaging was really important in Kenya to address some of the issues emerging early in PrEP rollout. The introduction of PrEP requires acknowledging that people may be at risk and highlights the unknown of what partners are doing. In Kenya, there was a lot of effort to engage religious leaders so that PrEP delivery is allowed/can continue. ARV-delivery sites are challenged to deliver PrEP outside of serodiscordant couples, as it isn't a location already accessed by other populations at risk for HIV. Approaches to mitigate stigma in this setting were put into place, including fast tracking HIV negative clients. Establishing one stop shops has also been helpful, so that those who want PrEP can quickly come in and leave. Establishing flexible hours within the ARV-delivery sites allows clients to come earlier or later in the day. Messaging 'PrEP for all' helps reduce stigma; it does not open a Pandora's Box of the worried well wanting PrEP. PrEP uptake is high in Kenya, but it has not been shown that the system is flooded with people at low risk of HIV wanting PrEP.

7. **In our current era of remote work and limiting face-to-face gatherings when possible, it is critical to think of creative ways to engage with clients. Have there been thoughts of making the stigma trainings virtually accessible?**

Some of the interventions are conducive to virtual methodologies. An NIH-funded randomized controlled trial led by UCSF and St. John's University in Bangalore, with RTI as a partner, is just finishing testing a blended learning approach for stigma-reduction for nursing students and ward staff in India that combines self-learning on tablets and one in-person session. In-person facilitation is specifically desired for stigma reduction but is not always possible. The MOH in Thailand, as part of their national HIV strategy, is scaling up stigma-reduction in health facilities, combining an approach similar to the HP+ one presented, but also including an e-learning component.

8. Can you attribute changes in stigma to changes to service delivery uptake?

To do so requires a long-term mixed-methods longitudinal research design because isolating the effect of stigma-reduction from everything else that is going on in health facilities and the community is complicated and to be honest, the 'appetite' from donors to fund this kind and level of stigma research has yet to emerge. Therefore, it has yet to be done. What we do have is a strong theory of change and evidence for pieces of that theory of change. There is a continually growing and significant literature that shows how stigma undermines each step of the prevention through treatment cascade, including recent work that shows a direct link between stigma and viral load suppression, independent of the intervening cascade steps. There is also growing evidence that stigma-reduction interventions, particularly in health facilities, reduce stigma.

ADDITIONAL RESOURCES

Additional resources related to addressing provider stigma in PrEP delivery settings can be found here:

- Language is a powerful tool to stigmatize, and de-stigmatize and one of the concrete ways we can all work on reducing stigma. We encourage attendees to reference and share this helpful document on terminology guidelines developed by UNAIDS in 2015: https://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf
- General HP+ health care toolkit that includes tools to measure HIV stigma and discrimination among health facility staff, train health workers and support facility administrators and managers in ongoing efforts to provide stigma-free services: http://www.healthpolicyproject.com/index.cfm?ID=StigmaPackage
- HP+ Guide for Trainers (Tanzania): http://www.healthpolicyplus.com/ns/pubs/10238-10428_TZStimgaFreeFacilitiesTrainerGuide.pdf
- HP+ Guide for Trainers (Ghana): http://www.healthpolicyplus.com/ns/pubs/10255-10465_GhanaSDFacilitatorsGuide.pdf
- Evaluation paper on the Ghana HP+ stigma-reduction intervention: ***Results from a difference-in-differences evaluation of health facility HIV and key population stigma-reduction interventions in Ghana*** https://onlinelibrary.wiley.com/doi/10.1002/jia2.25483
- The Health4All training developed under LINKAGES is available here: https://www.fhi360.org/resource/health4all

ADDITIONAL RESOURCES (continued)

- South Africa PrEP4Youth Public Service Announcements and oral presentation including more on background and development.
- Available in AIDS in September:
  - From the HP+ intervention in Ghana and Tanzania: ***A Total Facility Approach to Reducing HIV Stigma in Health Facilities: Implementation Process and Lessons Learned***. AIDS (in press).
  - From the Thai experience of making stigma-reduction a part of the national strategy and scaling up stigma-reduction programs and stigma measurement: ***Integration and scale-up of HIV-related stigma measurement and reduction towards ending AIDS: the experience of Thailand***. AIDS (in press).

We hope you join us again on August 27! Our next webinar will focus on providing PrEP through community-based delivery mechanisms. Presenters will include The Luke Commission in Eswatini and Right to Care in South Africa. Visit the PrEP Virtual Learning Network for more information on previous or upcoming sessions.