

Counselling to Optimize Adherence, Choice, and Honest Reporting
October 2018

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The Counselor Study Has Begun!

To date, we have launched (and almost completed!) the Counselor Study at seven study sites in South Africa, which were the first to secure IRB approvals. The study is still undergoing IRB review at the remaining sites. As soon as we have IRB approvals, we will launch the study at those sites!

If you will be leaving your site at the end of the HOPE study, you can still take part in the Counselor Study, just please email Cody at cody.lentz@nyspi.columbia.edu to give him an email address where we can reach you. If you will not have a computer, don't worry, you can also complete the questionnaire on your smartphone!





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Reflections from the Raters

As the study is winding down and there are fewer counselling sessions every day, we asked the raters to reflect on their experiences working with the counsellors on this study. Take a look at their reflections below.



Clare Kajura-Manyindo, Rater for the Uganda site

I always look forward to an email from Cody or Rebecca inviting me to come to the office to rate the uploaded sessions. Listening to the sessions by the Kampala team has not only kept me connected to my home, but has also enlightened me on the day-to-day experiences and health concerns of women in Uganda. It has been such a pleasure being a part of this great initiative, which provides women with an opportunity to make important choices pertaining to their health, with a focus on reducing the impact of HIV/AIDS. I am thrilled to see the counsellors perfect their use of *Options* counseling and quite often I cannot help chuckling when a conversation goes well, especially with the humor-packed Kampala sessions.

The continuous emphasis on a client-centered approach has become a reference point in my personal and professional life. As an instructor in the Graduate counseling program, I have integrated these skills into my instruction and communication with students. Feedback from students indicates that they feel safe, understood, and comfortable sharing their views without feeling judged, all of which are grounded in the global skills of respect, collaboration, autonomy, evocation and direction. I never end any discussion or conversation without asking the magic question: "what else?". It has been wonderful working with the Hope Study team in New York, which quickly became more like family. I cherish the professional and personal relationships built with the entire team.



NoCamagu Tuswa-Haynes, Rater for the Cape Town and WRHI sites

In all aspects of my career as a public/community pharmacist, patient counselling has always been central to the services I provide. What became apparently different from the counselling I had been doing to that used in the HOPE Study was the element of choice. I learned that the participants were not patients who had already been diagnosed with some illness; unlike my previous work, it wasn't my job to improve their outcomes, often using phrases like "or else" in my advice. I started to view my patients from a different perspective, to see how much they depended on my feedback, how I reflected on them, and how important it was for them to have a choice when discussing how they could improve their lives. Now, I can eloquently describe the difference between preventive measures and maintenance of a disease state with more empathy than ever.

The opportunity to work with people in my own country towards HIV prevention was an added bonus. It was something that came naturally as a woman trying to help other women, and listening to the counsellors try to convey a message of choice was inspiring. The most beautiful part was the counsellors being able to switch languages when needed, allowing them to reach into the participant's thoughts and make them feel understood, while still knowing that we (the raters) would be able to understand the conversation.





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Lonely Kachenjera, Rater for the Malawi sites

I was privileged to have been given an opportunity to work as a rater in the Study. I am proud to state that my work has sharpened my ability to constructively critique others through team-work (IRR monthly meetings). Many times, in the course of rating the sessions, I put myself in the shoes of the counselors and realized that my feedback to them was necessary to improve the way they approached and interacted with participants. Working on the Hope Study has also helped me pay attention to detail. Not only has my work enhanced my personal profile, but it has also made me a better person. I can now relate to other people better. The Hope Study also drew me closer to my fellow Malawians. I felt comfortable working with them. For example, while rating some sessions, I would pause for a moment to have a good laugh, owing to the sense of humor contained in the discussions.

Through my work as a rater in the Hope study, I have come to adopt the open-ended questioning technique that the counselors used during the sessions in my own teaching. I noted that participants were able to give as many answers as possible during the session, resulting in their positive participation. Additionally, not only did I rate the sessions, I also translated the English flip charts to Chichewa. This was a rewarding experience because, although I was away from Malawi, I was able to interact with the participants and relate to the seriousness of the HIV situation in Malawi. The participation of Malawian women in the study made me proud, as I know they have contributed a great deal in the fight against the spread of HIV. On reflection, I am aware that women are the primary caregivers to AIDS patients and children in Malawi. I daresay that if the spread of HIV can be halted through the findings of this study, women in my country have the opportunity to transfer their energies to other developmental issues, rather than spending a lot of time looking after patients. I am very proud of Malawian participants for taking that bold step to be a part of this study, which I believe will contribute effectively to preventing the spread of HIV in the world in general, and Malawi in particular. Women have a responsibility to ensure that they protect themselves from infection, and I am so proud of the Malawian participants for protecting themselves through their participation in Hope.

Lastly, I was privileged to participate in a high-level symposium (Young Women and PrEP), which was an eye opener to me regarding issues related to preventing the spread of HIV.



Zanele Ndlovu-Forde, Rater for the MRC sites Zulu sessions

Being part of the HOPE study has definitely prepared me for my current job. I now work as a Medical Assistant at a big medical office, and needless to say I come across all kinds of patients, some with gasp-inducing stories. Thankfully, HOPE taught me to not be judgmental, and I am proud to say that I have mastered that (on the outside, at least). Also rating the sessions always gave me such nostalgia that for a little bit I'd forget I was in the U.S. I'd get lost in the sessions, and going home to finally meet the counselors was unexpected icing on the cake. I'm forever grateful for the opportunity to be a part of this great, life-saving study, and I can't wait to see the ring accessible to everyone.



McLoddy Kadyamusuma, Rater for the Zimbabwe sites

I am amazed by how much being in the study has slowly changed how I handle conversations. I now always strive to be more respectful of others' views and opinions. Above all, I have seen myself grow in how empathetic I am towards peoples' feelings and situations. I have seen myself grow gradually and these are just some of the few things I will try to continue practicing in my life. Thank you, HOPE! I really enjoyed working with the Zimbabwean team. It was a great experience growing together in the best way to implement Options counseling. The Zim team was always ready to listen and eager to implement any suggested changes. This was probably one of the most worthwhile things I have done in a while since the AIDS pandemic has affected every single person in Zim in a way. It was great being part of such a team in helping to fight against HIV and AIDS.



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Cody Lentz, Project Coordinator, English Session Rater

Working on the HOPE study has definitely been one of the most memorable experiences of my life. It was a true blessing getting to help coordinate and know the ratings team, who quickly became like a quirky and joyous second family. The best part of these heartfelt connections, though, is that we were all united by a passion for our work and a fierce dedication to and appreciation for the counselors we rated. Though I didn't get to rate as often during the latter part of the study, I was consistently humbled by the hardships that women in the HOPE study were facing; beyond that, I was continuously impressed by how hard the counselors were working on the ground to really make a difference in the lives of these women. Their efforts are really what pushed me to want to be a better rater; I tried to put myself in the counselors' position and have that empathy be reflected in my feedback because I knew that any tiny bit of support I could give these amazing counselors would be worthwhile.

Meeting the counselors in Cape Town was far and beyond my best memory to date. The energy and sheer love that they bring to every meeting is inspiring, and really helped to broaden my perspective both on the HOPE study and life in general. The fact that we could have myriad people from different cultures coming together to work for such an impactful cause really resonated with me and reinvigorated my dedication to this line of work. At the end of the day, we are all people, and now I work extra hard to hold onto this fact when I'm interacting with others. In my interactions, I want to collaborate equally with others, to unfailingly show respect for their choices, to really make an effort to inquire about and understand their perspective. The counselors have taught me that everyone has something to offer and, if we just give people the chance (and kindly prod them with a well-timed "what else?"), most will open up and teach you a little more about their reality and how they see the world. These lessons have been invaluable; I can't thank the study team, the raters, and the counselors enough for helping me learn them.



Rebecca Giguere, Project Director, English Session Rater

Although I had been working on MTN studies for nine years when I started working with the HOPE team, collaborating with the counselors and the rating team on this study has been a wonderful learning opportunity. I have greatly enjoyed working with the raters, as they each bring unique perspectives and a great sense of humor to the table. Together, we strive to put ourselves in the counselors' shoes and to provide support to those who have one of the toughest jobs in this study: the counselors! I greatly admire the counselors for their hard work and dedication to the participants, and their openness to discuss challenges and successes with HIV prevention in a context where women cannot always take ownership of their bodies and their health. Of course, meeting many of the counselors in person at the MTN Regional Meeting last year was the highlight and the culmination of our work on this project. It brought home to me the point that, although we may all live in different places, we are partners working towards a common goal of empowering women to be free from HIV. This personal interaction was an incredible opportunity to learn from each other and reinforce our partnership. I look forward to sharing in the team's successes when we can say that we all played a small part in the approval of the first vaginal ring for HIV prevention!



Christine Rael, English Session Rater

Through my work on HOPE as a part of the COACH team, I've learned to apply a number of the communication strategies in my personal life. Specifically, I had a baby 10 weeks ago. Learning to focus on people's strengths in my communication has helped to keep my relationship with my partner and other family members strong, despite the newborn sleep deprivation, breastfeeding struggles and other changes that come with having a new baby. Additionally, being a part of the effort to develop tools to fight HIV has been incredibly special. Through this experience I've met so many amazing people, especially the other COACH team members, on-site counselors. I look forward to collaborating with the HOPE team in the future!



A Message from Ivan

My dear HOPE counselors!!!

How quickly two years pass!! It was in June 2016 when I first met some of you at the HOPE kick-off meeting in Durban....and how far we have come! This is the first study in which you had to record your counseling sessions, which I know can be very stressful, but look at what we achieved:

63 certified counselors 5,366 recorded sessions 1,238 sessions reviewed 83.9% of sessions were rated "fair" or "good"

As impressive as these numbers are, I think we achieved much, much more!!

- ✓ We elevated the role of counselors in a biomedical study
- ✓ You learned and embraced a new, more empathic way of interacting with participants and patients that both supported and motivated them
- ✓ You became empowered counselors and helped to empower women to voice their opinions about their preferred HIV prevention approaches
- ✓ You will now inform how counselors are trained and supported in future studies

I hope you are all proud of what we achieved in HOPE!!

Your warmth, generosity of spirit, eagerness to learn, and embrace of my team in New York made this an incredibly moving and fulfilling experience for me. As I write this I am reliving our wonderful times together in Durban and Cape Town and I will always cherish those memories. Thank you all for making this experience the highlight of my career!!