



‘In the CATS Lounge’

*A Report for ViiV Healthcare on the collaborative project
between SHM Foundation and Africaid Zvandiri*

June 2020

Introduction



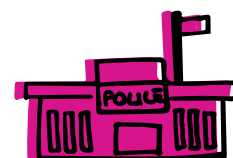
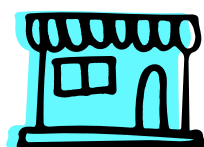
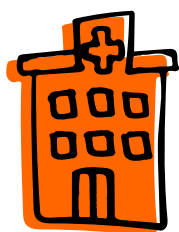
This is a findings report for ViiV Healthcare from the SHM Foundation in collaboration with Africaid Zvandiri. The report outlines how we used the funds that we generously received from the 'ViiV Healthcare's Positive Action Challenge Award' at the UN General Assembly. This award provided us with a very exciting opportunity, for the two organisations to collaborate for the first time.

Both the SHM Foundation and Africaid Zvandiri have a track record and interest in the power and opportunities that peer-to-peer models provide in giving critical ongoing support for those living with and affected by HIV. Peer mentors can help to support over-burdened health systems and provide much needed psychosocial support. While we both recognise the important role that peers can play in supporting other peers, we also recognise that there must be support systems in place to protect their own physical and mental health. This can be a challenge as these types of models expand it often becomes more challenging to have the right support systems that are both accessible and meet the range of diverse needs that peers might have. This award provided us with the opportunity to explore this challenge further by co-designing a support model via mobile phone with 70 adolescent peer supporters (CATs) in Zimbabwe; and to most importantly develop a pilot that we believe is scalable so as to provide the ongoing support that all peer mentors need.

Findings from our pilot have shown that there was a high uptake of the model, 89% of participants used the support groups. There were positive outcomes for the individual participants – they were more likely to disclose their status, there was a decrease in internalised stigma and a positive trend towards viral suppression. There were positive outcomes for Africaid and the SHM Foundation, with the pilot providing rich data on the topics that peer mentors may be grappling with which has helped both to see how they can address these issues in their programmes.

Co-Designing A Support System for the CATS

The Design Process



Both the SHM Foundation and Africaid Zvandiri believe that the **key to building a support system for peer supporters is to engage them at the very heart of the design process**. We ran 10 days of participatory co-design workshops with urban CATS from Harare, and rural CATS from Buhera. What was particularly special about our design process was that many of the **workshops were facilitated by the SHM Foundation's Khuluma mentors** – adolescents living with HIV who themselves act as peer supporters in SHM Foundation's projects in Pretoria and Cape Town, South Africa.

Over the course of this week we worked with 19 CATS, attended 4 home visits, conducted 4 days of workshops and visited 2 clinics. We used **creative, dramatic and artistic methods to understand what existing support structures the CATS have**, what their limits were, what their fears and challenges were in their daily life and in their work. We worked with the CATS to build prototypes of support systems, that we then integrated into a single solution.

Working alongside the CATS, we decided that their ideal support system had two distinct parts - a **'lounge' where they could access peer and professional support** informally anytime, anywhere, anonymously and a **'tool shed', that equipped them with the action and advice** they needed to fulfil their responsibilities as CATS and meet their own mental health needs.

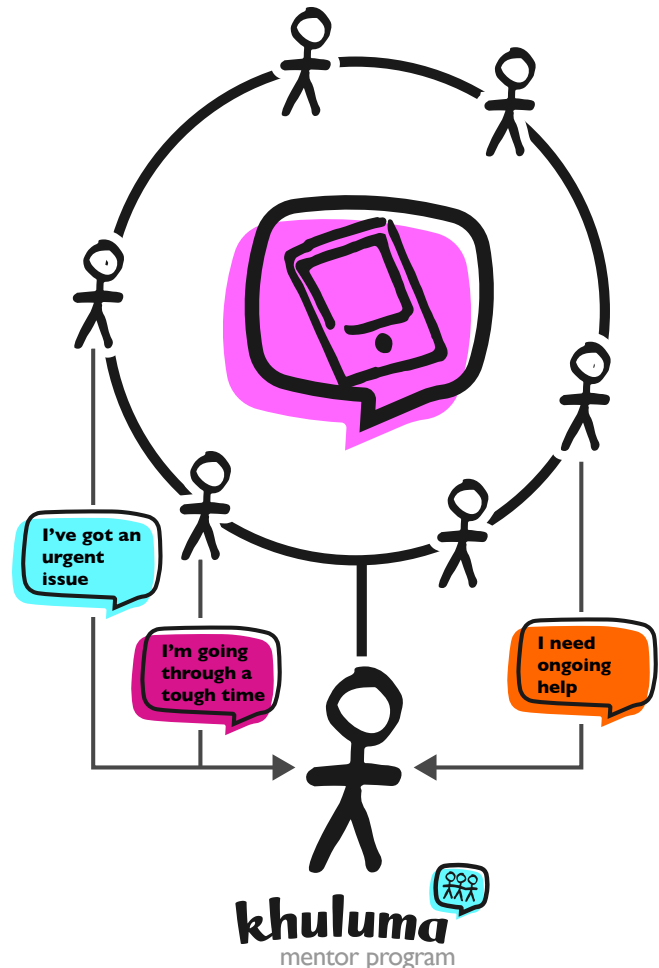
For the intervention phase we decided to focus on creating the virtual lounge as this seemed the area where there was the most need. **Our aim was to develop a model right from the beginning that could be scaled up if successful so as to be a regular day to day support system for the CATS**. Africaid is working on the development of the materials for the tool shed in parallel to complement the lounge in the future. Designing of the toolshed materials has involved building on insights from the immersion experience and data generated through the lounge about the CATS needs.

What is the Lounge?

The 'Lounge' that we developed is a mobile-phone peer-to-peer support group for 10-15 CATS, and an external facilitator. The participants could communicate at anytime, anywhere about the issues pertinent to their needs.

The groups were:

- **Confidential**
- **Anonymous**
- **Immediate**
- **Intimate**
- **Mixed Gender**
- **Adolescents Only**
- **Non-Judgmental**



How did it work?

We engaged participants from districts in and around Harare. Participants did not know one another and chose a nickname to mask their identity.

The six groups were mixed gender and were facilitated by a representative of the SHM Foundation team, a Khuluma mentor in South Africa and a CATS worker who had been given basic mentor training.

The groups ran for 3 months between November 2019 and January 2020. We used the digital messaging platform Rocket.Chat, to ensure the groups were anonymous and well administered, that they could not exchange numbers, upload content or forward messages. In the groups, participants discussed issues pertinent to their needs.

Two guest speakers were invited to discuss key issues that came up – a psychologist to discuss disclosure, and a careers counselor to discuss employment. The groups were critical pathways for referral of adolescents who needed more acute care from the psychologist or to their district mentor. The groups were monitored by the senior SHM Foundation and Zvandiri teams.

Key Findings

Through our evaluation methodology (see Appendix 1), we found the following;

1. The uptake of our model was high, showing that it was engaging for the participants.

- 89% of participants engaged in the model.
- 2195 messages were sent in the groups.
- An average of 14 participants sent messages each day
- Participants found Rocket.Chat an easy technology to use and liked that it provided anonymity.
- Participants discussed a range of topics including disclosure, stigma, social support, relationships, sex, physical and mental health and the future. The sensitivity of the topics showed that it was a safe space where they felt comfortable to discuss issues pertinent to their needs that they wouldn't bring up elsewhere.
- Facilitation by an external trained figure, in this case from the SHM Foundation team, was key to this high level of engagement.

2. The model had a positive impact on the individuals taking place in the program, particularly with respect to increasing disclosure, decreasing internalized stigma and improving medical adherence.

2.1 Improving Disclosure

Participants used the groups to discuss issues of **disclosure** to family and partners. The CATS even used the groups to help them disclose their status to their partners or peers. **Only 7 of the CATS had disclosed to their partner before the intervention, but afterwards 24 reported that they had.**

I haven't disclosed yet to all the girls I had how do I do it

Transporter

@Jamaican @Keketo do you have any suggestions to help @Transporter with disclosure to his girlfriend?

Disclosure is a process and it's your choice. We can think about the pros and cons.

Lounge_Admin

Yaaa it's true it's a choice and u have to know that either she is going to accept you or not put this in your mind... And if you're not ready to do that don't force yr self but on that note never had unprotected sex

Jamaican

I suggest you have to talk to yo girlfriend privately and face to face. Then tell her yo status ..and see the next reaction ...

Classical

Ok thanks guys for the advice. I will definitely try it

Transporter

2.2 Decreasing Internalised Stigma

The CATS reported a high incidence of **internalised stigma** before the intervention, this notably decreased after the intervention across all three items, as summarised in the table below. Indeed, before the intervention 22% of the CATs indicated that they had lost respect or standing in their

community because of their status (agree or strongly agree), compared to 15% after the intervention.

48% indicated that they thought less of themselves because of their status before the intervention, compared to only 9% after the intervention.

Question	Strongly Disagree		Disagree		Agree		Strongly Agree	
	Before	After	Before	After	Before	After	Before	After
I have lost respect or standing in the community because of my HIV status	22%	11%	56%	74%	20%	15%	2%	0%
I think less of myself because of my HIV status	17%	9%	35%	81%	37%	7%	11%	2%
I have felt ashamed because of my HIV status	26%	13%	39%	74%	30%	13%	6%	0

2.3 A Positive Trend Toward Medical Adherence

We recorded a positive trend in **viral suppression**. At the start of the intervention, 89% of CATS were virologically suppressed; 8 of the 54 CATS (15%) had unsuppressed viral loads. At the end of the intervention, 5 of these 8 were virally suppressed and 3 had pending results. Though we cannot directly attribute this change to the intervention, this is an area for further study.

Yet the CATS did explore the challenges they were facing taking their pills in the groups and in the questionnaire. Despite the fact that they were always encouraging each other to adhere to ART, the CATS discussed their own challenges with taking their medication. These **challenges were related to fear of inadvertent disclosure, stress, side effects, peer pressure, complications due to faith healing, difficulty swallowing, stigma and discrimination.**

“Sometimes adolescents they give up because he or she might be the only person who is taking medication in their family therefore stigma and discrimination is common in such situations. ... factors that lead to poor adherence is that: parents sometimes afraid to inform their children that they are HIV positive, this can lead to a child not to adhere well because he has no knowledge. Some adolescent they are married and failed to disclose their status to his or her partner so they usually stop taking medication or they take but not everyday.”

- Tinotenda

3. *The model had a positive impact for Africaid, as it provided rich data on the day-to-day challenges faced by the peer mentors that can help them to improve services.*

The support groups provided Zvandiri with an insight into the needs of the CATS that they were unable to access otherwise. Some of these included:

- The CATS often found it **hard to separate their own needs from those of their beneficiaries.**
- The CATS often felt that they **couldn't do enough for their beneficiaries.**
- The CATS were sometimes **concerned about having to disclose their own status to the beneficiaries.**
- The CATS **spoke a lot about stress**, a theme not usually addressed by the program.
- The CATS need **support with their future plans and careers**, particularly if they are nearing 24.

These insights will be fed back into the design of the program, including their training, curriculum and support structure for the CATS.



Learnings for the Future

We learnt much about the needs of peer supporters, and the potential for digital support groups to meet these needs. However, there are a number of challenges that we identified that we will address as we move forward and scale up:

- The inconsistency of the mobile network for the CATS prevented them from participating, however engagement remained high. Individuals would sometimes be absent for days and apologise when they returned. If they travelled out of Harare, this problem grew worse. In the future, **we will do more testing of the mobile networks in places where participants are active.**
- The inconsistency of electricity prevented them from charging their phones, and thus from participating. They were able to charge their phones when they came into the Zvandiri house facility. Participants also discussed techniques and solutions to this problem in the groups. In the future, **we will provide alternative charging methods for participants such as solar chargers.**
- The phones themselves were not ideal models. They overheated over the course of the intervention, and many had technical issues that meant they had to be fixed by the Zvandiri team or were unable to be used at all. In the future, **we will provide a better model of mobile device.**
- The groups ran over the course of the Christmas period resulting in limited staff to facilitate and monitor the groups. In the future, **we will not run groups over a holiday period.**

What next?

It is clear from the focus group and the questionnaire that the CATS liked using the platform, and it was particularly useful to them because they were **able to remain anonymous** when they shared some of the most intimate problems they were facing.

As we move forward, Zvandiri could integrate this kind of model for their CATS across the country to ensure that they have an accessible, facilitated and intimate support mechanism at scale. This would help Zvandiri to engage and support CATS with issues that they could not support with otherwise including disclosure, their relationships and future prospects, and to augment the referral systems across their districts. The model provides a new way for Zvandiri to engage young people who are unable or unwilling to participate in their support group program due to barriers of time, stigma and logistics; improving support outcomes which will in-turn have a positive impact on access to services and information.

Indeed, Zvandiri have identified an important opportunity to replicate the model across the districts of Zimbabwe in which they are active. It is clear through the pilot that the impact of the model could be scaled. The advent of the Covid-19 pandemic has only brought into sharper relief the need for virtual approaches to supporting the CATS that overcome barriers of access to peers, training, up to date information and psychosocial support, but maintain anonymity and intimacy.

In the next iteration of the model, we hope to achieve the following advances in the model design;

1. **We hope to better design a feedback mechanism** that would allow the anonymised data from the groups about the CATS needs and challenges to be fed into the operational team in real time, so they can respond effectively to new forms of vulnerability that perhaps were not visible before the pandemic.
2. **We hope to further develop engagement between the Zvandiri professional psychological team and the groups**, allowing psychologists to run sessions and facilitate groups so as to strengthen the quality of information provided and the referral mechanism.
3. **To provide further training for the CATs who were very effective and involved** in the pilot so that they are able to facilitate groups themselves.

The potential of the model for supporting peer supporters world-wide is also clear. The SHM Foundation could pursue this as a way of extending the impact of their mobile phone model. We see particular opportunity to replicate this model with other adolescent peer led organisations who are working in stigmatised conditions like HIV, mental health, diabetes and forms of disability. However, in order for it to be successfully replicated, we would need to ensure:

- That we always map the existing support network that the peer supporters have, and the primary challenges that they face.
- That we are able to maintain the independence of the space away from the peer supporter's employer to ensure that it is open and honest.
- That we have a strong connection to a source of correct health advice so as to ensure our messaging and advice aligns with that of our partner.

Building tailored, anonymous mobile phone-based support systems for peer supporters to share the challenges they face in their own lives will produce better health outcomes for both the supporters and their beneficiaries. We believe allowing access to intimate, immediate and accessible support is the future of peer-led interventions.

Appendix I: Evaluation Methodology

We used a mixed methods approach to evaluate the impact of the intervention. This involved a pre and post intervention interview with the participants in the groups and a small control group. We asked about issues like their perceived social support, internalised social stigma, ability to support their beneficiaries, hope and self-reported adherence. We also ran a focus group at the end of the intervention. Last, we analysed the content of the anonymised text messages generated by the intervention to understand what the CATs wanted to discuss and how they supported one another.

Pre and Post Intervention Questionnaire

The Pre and post intervention questionnaires were a revised and adapted version of the SHM Foundation's Khuluma and Insaka questionnaires. The questionnaire was administered to 54 participants at the beginning of the study, when they gave informed consent. It was administered again on follow up 4 months from the baseline, when the intervention had come to a close. It included the following validated instruments:

- **Internalised stigma** measured using a three-item internalised score (used in the PopART study) .
- **Hope**, measured using a scale validated among young people in South Africa .
- **Social support**, measured using an adapted version of the MHPSS .

Text Message Analysis

The intervention generated text messages from six groups. In order to analyse this data, six investigators were each given one group's data in Microsoft Excel files from one of the six groups. Following the method defined by Braun and Clarke (2006) , investigators first familiarised themselves with the transcripts, and began making thematic annotations. Investigators then coded the data independently. Third, investigators met and discussed the codes they had generated, collating codes under key themes. One investigator developed a code book with key themes. Fourth, investigators applied this codebook to the data, and discussed a number of additions and subtractions to agree on themes. Investigators indexed the data sample across the themes. Finally, investigators met to define, name and interpret the themes, specific to the overall story told by the data. This report presents preliminary thematic findings after initial rounds of coding. The presentation of themes in this document does not include this cultural validation process.

¹ Hargreaves JR, Krishnaratne S, Mathema H, et al. Individual and community-level risk factors for HIV stigma in 21 Zambian and South African communities: analysis of data from the HPTN071 (PopART) study. *AIDS*. 2018;32(6):783-793. doi:10.1097/QAD.0000000000001757.

² Abler L, Hill L, Maman S, et al. Hope Matters: Developing and Validating a Measure of Future Expectations Among Young Women in a High HIV Prevalence Setting in Rural South Africa (HPTN 068). *AIDS Behav*. 2017;21(7):2156-2166. doi:10.1007/s10461-016-1523-6.

³ Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52, 30-41.

⁴ Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2), pp. 77-101. ISSN 1478-0887 Available from: <http://eprints.uwe.ac.uk/11735>