



# HIV TESTING A YOUTH CENTRED APPROACH



# Introduction

South Africa has the largest HIV epidemic in the world, with an estimated 7.2 million people living with HIV<sup>1</sup>. Young people are particularly vulnerable to HIV infection and account for approximately 45% of all new HIV infections worldwide. Tragically, HIV is now the leading cause of death among 10 to 24 year-olds in Africa<sup>2</sup>. Antiretroviral Therapy (ART), the only effective treatment for HIV, requires strict patient adherence. Poor levels of ART adherence among adolescents and young adults in South Africa have been reported<sup>3,4</sup>.

Effective communication and the need for youth-centred interventions to promote long-term optimal ART adherence have been prioritised in the South African National Strategic Plan on HIV, TB and STIs 2017 – 2022. Several health professionals, including doctors, nurses and pharmacists in the ART clinics, communicate ART adherence messages to young people. However, trained lay counsellors play a

pivotal role in HIV testing and ART initiation, and are the main channel of communication for adherence promotion.

Recent research<sup>5</sup> found that current communications about treatment were limited in their effectiveness, and rates of treatment adherence remained poor. Three central factors were identified that contribute to ineffective communication in the HIV test process:

## Didactic communication

Treatment knowledge was seen as a significant issue as it focusses on 'telling' young people what to do, rather than enabling them to learn about why they need to adhere to ART. Clinicians recognised that this approach needed to change as many young people left the clinics having not understood, or in some cases having misinterpreted, their explanations about treatment.

<sup>1</sup> Unaid 2018. UNAIDS Data 2018. New York: Joint United Nations Programme on HIV/AIDS (UNAIDS).

<sup>2</sup> UNICEF (2017) 'Statistical Tables'

<sup>3</sup> Zandoni, B. C., Archary, M., Buchan, S., Katz, I. T. & Haberer, J. E. 2016. Systematic review and meta-analysis of the adolescent HIV continuum of care in South Africa: the Cresting Wave. *BMJ Global Health*, 1, e000004. doi:10.1136/bmjgh-2015-000004.

<sup>4</sup> Hornschuh, S., Dietrich, J. J., Tshabalala, C. & Laher, F. 2017. Antiretroviral Treatment Adherence: Knowledge and Experiences among Adolescents and Young Adults in Soweto, South Africa. *AIDS Research and Treatment*, 2017, Article ID 5192516. doi:10.1155/2017/5192516.

<sup>5</sup> Hickson, 2016. An interdisciplinary study exploring how health communication can most effectively explain Antiretroviral Medication (ART) and motivate adherence among young people

## Behavioural models

Adherence communication is informed by health belief theories that focus on individuals' cognition only and seek to inform and shift peoples understanding of two factors: perceived risk of disease and health benefit. This understanding is presumed to be a central determinant of a person's motivation to adherence to a health behaviour. Commonly cited as the euro-centric 'top-down' approach, these models are found to provide disappointing levels of change, especially among adolescents. This has been especially noted when they have been used to inform HIV prevention campaigns in sub-Saharan African communities.

## Communication barriers

The third factor was specific to a series of barriers that limited the effectiveness of current communication:

- Low literacy and education levels were an obvious barrier to understanding of written materials.
- Rumours in the community about treatment caused confusion among young people.

- Complex concepts such as the relationship between infection, CD4 count, and undetectable viral load, and why it is so important to take antiretroviral treatment every day within a narrow window of time, were particularly difficult for young people to understand.
- In face to face situations, some clinicians used complex medical terms to describe these factors without sufficient explanation. Often, there simply wasn't enough time to explain things thoroughly.
- Metaphors were also used by some clinicians as a way to simplify the information. However, data analysis suggested that the use of metaphors created further confusion. This has also been documented in other places.
- The inconsistency in the language and images used across the care pathway was in itself a further source of confusion.

All these factors led to misinterpretation and, in some cases, failure to follow the treatment regime.



Figure 1 shows how behavioural models inform the message structure and didactic approach used in HIV testing and treatment counselling



# Listening to young people

Young people said that current communications about treatment were limited in their effectiveness and rates of treatment adherence remained poor. This was partly because many young people did not understand what they were told about treatment and the importance of following the treatment regime. However, it was also linked to deeper issues of motivation, which were related to the trauma of diagnosis and a loss of hope. Therefore in order to improve communication effectiveness, it will be essential to address motivational issues as well as issues of understanding.

## Diagnosis trauma

When young people were first diagnosed as HIV-positive, they were too traumatized to take in what clinicians said to them. Then, as the initial shock died down, many young people still failed to become motivated to learn about treatment because they had lost all hope of a normal life. Many of them had lost parents or other family members to AIDS, and they had an overwhelming fear of becoming sick and suffering an early death. Often, they had an even greater fear that they would be rejected by their family and friends because of the stigma connected to HIV.

These emotions were open to interpretation that were based upon the imagined emotional response of significant others which included

disappointment, rejection and anger. Others are seen as the primary influence, which combined with treatment confusion, a lack of knowledge, and HIV-related trauma become a person's 'internal reference point', which then becomes the principle determinant to how they define and behaviourally respond to a situation. This process is illustrated in the adjacent graphic (Fig. 2), that shows how a young person often responds to an HIV-positive diagnosis that determines their behavioural response.

## Motivation: regaining hope

Restoring hope was recognised by young people as a vital factor in helping them move towards successful treatment. However, regaining hope and motivation was not only dependent on understanding about treatment only. Young people also talked about the importance of being able to reconnect with at least one person to whom they were close, especially a family member, who accepted and supported them in spite of their new diagnosis. Reconnecting with someone in this way affirmed their identity - as a son, a daughter, a cousin or a close friend. This in turn gave them hope and made them motivated to learn more about the treatment regime and adhere to it. This is an important finding as it locates belonging as a central determinant for young people's motivation to adherence.

## Understanding the crisis event of a HIV diagnosis or disclosure

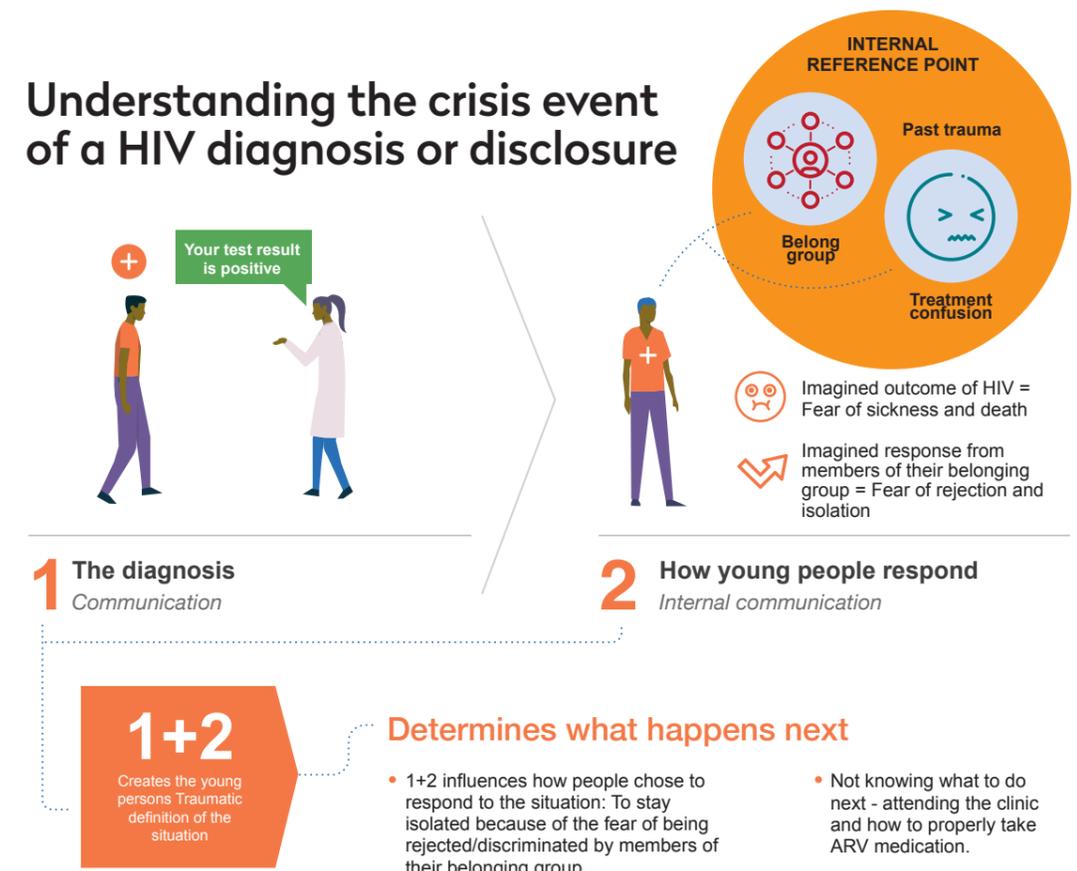


Figure 2 shows how a young person often responds to an HIV positive diagnosis that determines their behavioural response.



## How young people said they wanted to be tested

Young people described how they wanted HIV communication to become more compassionate and youth-friendly, which included two new visual communication tools that were developed and tested during the study: a film and an animation.

### **A film that communicates hope: Coming to terms with HIV**

To help support them through the trauma of diagnosis and give them hope, young people had said that they wanted to listen to other young people's stories of how they had moved forward. Accordingly, a film was made presenting the story of one young person who overcame his initial diagnosis shock and, through the acceptance and support of his family, learned to live a normal life with HIV.



A young man who lives with HIV using the animation that was developed during this study, designed to explain ART adherence, during the pilot study at the youth clinic.

### **The animation: Explaining the medical basis for antiretroviral treatment**

Young people said that an animation might help them to better understand the medical basis for antiretroviral treatment and the treatment regime. Accordingly, an animation was produced explaining the concepts of viral load and CD4 count. Rather than using metaphors, it used isotype as the central visual language\*. Other details of the visual representation were developed in consultation with clinicians and young people.

### **Communication contexts: creating spaces for sharing and learning**

The pilot animation was presented to groups of young people at one of the clinics by a young man who himself was living with HIV. During presentations of the pilot animation, young people talked passionately about their own experiences, including the loss of family members, friends and community members to HIV in the past.

\* Extensive research shows that Isotype (International System of Typographic Picture Education) is the most effective visual language used to communicate medicine instructions, especially to low-literate populations. Pictograms are also the visual language recommended by various international pharmaceutical conventions.



Many of them had not done so before and found it very helpful. They also asked many questions about HIV and treatment, and a dialogue developed. This kind of exchange was valued greatly by them. It is probable that communication will be more effective in settings that provide a space for sharing and learning of this kind than in conventional one-way transmission of information.

- Message targeting: increasing acceptance and understanding in the community. A finding that emerged strongly from the data was that it is not only people living with HIV who wish to gain a better understanding of antiretroviral treatment:
- Many young people said that they wanted to learn about treatment irrespective of their test result, so that they could support friends and family members who lived with HIV. It would also make them better prepared if they were to become infected themselves.

Building upon this research the mCommunication tool was further developed and piloted in South Africa. The project was funded by ViiV Health.

## Piloting a new approach:

A prospective cohort pilot study was conducted to determine the acceptability, feasibility and efficacy of the mCommunication tool among adolescents and young people aged 18- 26 who were attending one of two HIV facilities in Khayelitsha township near Cape Town.

Data collection took place during a total of six months between 2017 and 2018. Participants were purposively sampled using a mediated access approach. All participants (n=78) presenting for HIV testing completed a mixed methods questionnaire, capturing ordinal and qualitative data. At the beginning of the questionnaire, participants provided a hope score (categories 1 (low) - 6 (high)). The multimedia was then presented, allowing for discussion and learning. Participants were then asked to repeat their hope scores.

Participants who tested positive were then enrolled onto the study. Post-test, the intervention was repeated. Those who tested HIV positive (=12) received follow up during the four-month study period.

### **Data analysis**

Ordinal data were analysed to show existing variables across the hope categories. Thematic analysis was used to identify, analysis and report patterns that emerged from participants responses.

# The tool design

## Increasing HIV literacy

Using the principles of Human Centred Design (HCD), a digital communication tool was co-designed with young people and healthcare workers. Both design and functionality incorporating all aspects of what young people had said were important to them in the context of HIV communication (as described above).

## The tool included:

### The Learning zone

Animation designs were informed by Mayers theory of multi-media learning<sup>6</sup>. According to Mayer, presented information should be “segmented” in repeatable sections, allowing the learner to move through the information according to their cognitive capacity, which prevents an overload to the working memory that is essential to their learning experience.

In response to the study findings, the animations focused on explaining the complexity of biomedical concepts of infection and treatment, in particular why it is essential to take medication regularly, how ART achieves viral suppression, and why viral resistance occurs as an outcome of sub-optimal adherence.

Six animations were developed that followed six stages of adherence learning, informed by PK data\*\* related to ART. Figure 3 shows how the medication fluctuates between doses (called the PK curve). Maintaining optimal adherence during a person's lifetime is essential to achieve and maintain an undetectable viral load. Figure 4 shows what happens when doses are regularly missed, causing an increase of viral load, resulting in viral resistance and the need for the patient to move to another drug regime. Currently, in South Africa, only three regimes are available through the public health system.

LEE - a story about a young man living with HIV and successfully adhering to his medication was included, bringing to life the reality of the power of ART.

\*\* PK data refers to the four processes that encompass the pharmacokinetics of a medication. They are absorption, distribution, metabolism, and excretion. Each of these processes is influenced by the route of administration and the functioning of body organs.

<sup>6</sup> Mayer, R.E. 2009. Multimedia learning. Cambridge university press.

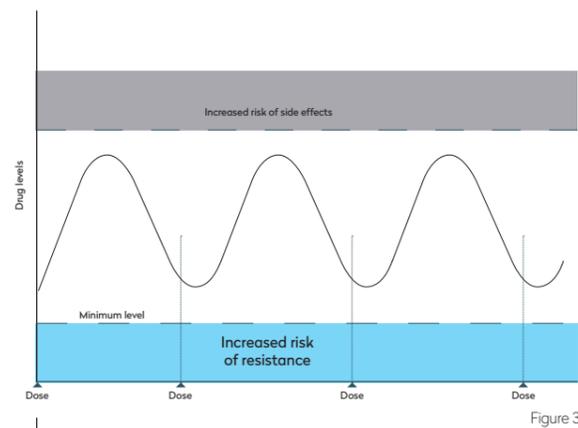
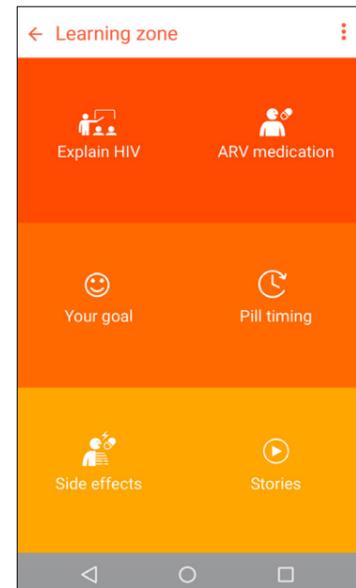


Figure 3

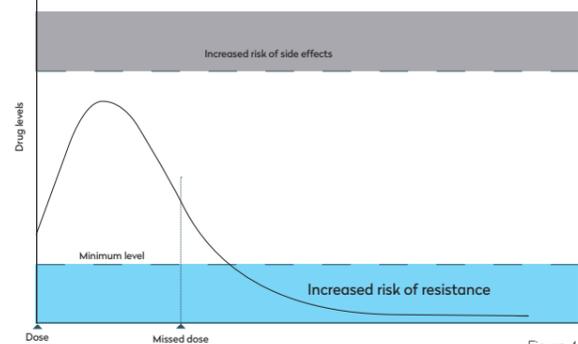


Figure 4.



## The 6 stages to adherence learning:

- 1

**Explaining HIV**

Accept · Support · Belong

▶

https://vimeo.com/425468172

Explaining how the disease works in a person's body is essential learning that provides the foundation to why therapy has been prescribed and how it combats the disease.
- 2

**ARV medication**

Accept · Support · Belong

▶

https://vimeo.com/425468899

Stage 2 describes how medicine combats infection and achieves viral suppression. Consequences of non-adherence are also clearly explained.
- 3

**YOUR Goal**

Accept · Support · Belong

▶

https://vimeo.com/425468807

Stage 3 learning is to reinforce the primary goal of treatment - to achieve and maintain an undetectable viral load.
- 4

**Pill timing**

Accept · Support · Belong

▶

https://vimeo.com/425468540

Stage 4 frames pill timing in the context of a 'therapeutic partnership' required to achieve and maintain an undetectable viral load.
- 5

**Explaining side-effects**

Accept · Support · Belong

▶

https://vimeo.com/425480453

Side effects are common anxiety among young people. Stage 5 carefully explains what they are and what a patient should do about them.
- 6

Once

Your next pill

03:00 AM

Consolidation of learning. This graphic summarises how the medication reduces in a patients system and was linked to a pill time reminder, visualising each day that they are running low and need to 'top-up' to maintain viral suppression.

# Key findings:

## Hope score 1

Participants (n=78) were asked to score their feeling of hope before they were shown the multimedia. Results are shown in figure 5. Four themes emerged from the qualitative data that explain participants' reasons for their initial hope scores:

### Traumatic talk

Young people described that they would feel traumatised in the event of an HIV-positive test result (mostly evident across scores 1-2). For many, the idea of testing positive felt catastrophic, with answers only focusing on feelings of despair and hopelessness. For some, they believed it would be the end of their world, leaving them without a future. Others spoke about their fear of death, rejection from family and friends, and not knowing what to do.

*"I would feel bad because I don't know what I would do with my life and I don't know who I would talk to. Level 1 because I don't have hope, like I said I don't know what I would do with my life".*

### Acceptance talk

In contrast to the above, some young people described how they would accept a positive test result, evidenced across all of the hope score categories. A particular characteristic of these responses was that they did not reference negative emotions, such as fear, hopelessness etc. Descriptions included how they would accept their results because it cannot be changed. These answers often referenced treatment, that being positive would not change their identities, or that a diagnosis would not be the end of the world. Others said that they felt confident that they could manage the disease because they knew people who were living with HIV, and would receive support from family, friends and support groups.

*"I would accept it because HIV is a disease which people live with. I would rate my hope as 6, because nothing changes about you, its just a disease in your body."*

Three young people said that they would accept their status because they were not using a condom and were expecting a positive test result.

### Rational talk

These responses were a combination of traumatic and acceptance talk. Initial responses mirrored the descriptions in the traumatic category, followed by acceptance talk that similarly reflected the themes described in the acceptance talk category.

*"I am very scared but I know it wouldn't be the end of the world for me, yes it would be shocking because my life won't be the same, but I would learn to accept my situation".*

Three participants provided no answers. Research assistants noted that this was mostly due to some participants finding it to be challenging to talk about the possibility of testing positive. Two responses were ambivalent, providing no insight to their score value.

## Impact of animations

### New learning

The majority of young people reported that they had learnt new things about HIV infection and treatment. New learning was attributed to:

- Gaining a new understanding of how ART works in the body.
- How ART reduces the viral load, resulting in an 'undetectable viral load'.
- Viral resistance: the implications of non-adherence, resulting in having to change to new ART regimes, with only three lines available.

*"I have seen and understood how treatment works, how one moves from one line to another if they don't take their treatment as they should. So I have learnt that it is important to take your medication so you can stay healthy".*

### Giving hope

Respondents described the animations as encouraging, providing them with hope. This was mostly due to the feeling that they could manage HIV because they now understood how the treatment works.

*"I have learnt that when you are HIV positive it doesn't mean that it will be the end of the world for you, so what you need to do is take your medication".*

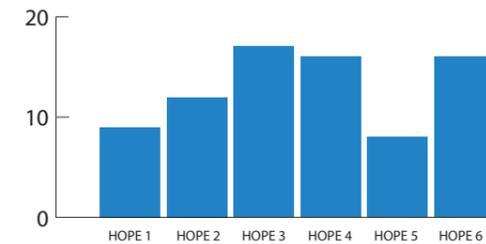


Figure 5. Pre-intervention hope scores

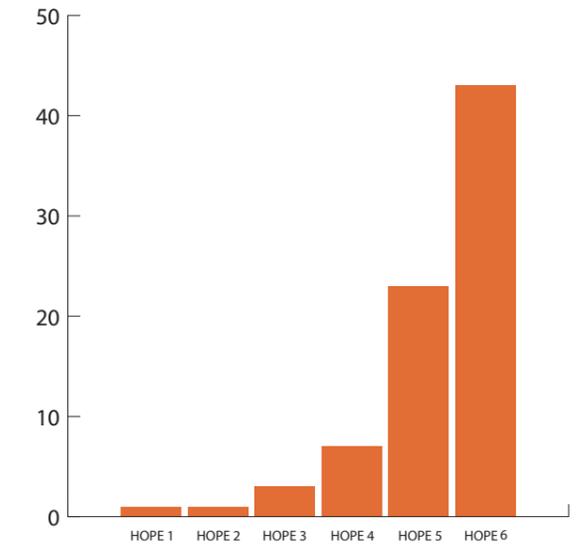


Figure 6. Post-intervention hope scores

### Community benefit

Participants described how the animations would benefit their communities because others could learn about HIV and treatment. This was also related to young people saying that the animations would also prompt either themselves or others to take treatment and 'condomise' to prevent HIV infection.

## Impact of the film

### Motivational

Many participants found the film story motivational. Motivation comprised the following three themes:

- Encouraging: Young people found the film story inspired them to accept themselves and have hope for their present and future lives.
- Supporting: Providing hope that their families would also accept and help them in the same way described in the story
- Inspiring: Participants described how the story of Lee inspired them that they too could live a full and healthy life with HIV.

*"I think it's a good film, because it encourages people to love themselves no matter how they are".*

### Coaching

Young people also described how the film message helped them to know what to do in the event of an HIV diagnosis. This was defined as taking treatment properly, gaining support from a trusted member of their family or friend and the importance of self acceptance.

*"The film I see that it's a very good thing because as I see this person on it, it's that he has accepted it. The key message is that once you find yourself HIV positive, you need to love and support yourself so that people can do the same to you".*

### Coaching

Respondents reported that they would like to show the animations to members of their families, friends and community members.

Finally, one participant said that she had not learnt anything from the film:

*"I knew everything in regard to what the film has said".*

## Post media hope scores:

After the intervention had been presented, participants were asked to re-score their feelings of hope. 67.9% (n=53) reported an improved hope score. 28.20% (n=22) participants reported no increase to their original hope scores (See fig. 6). Three participants reported lower scores. Two respondent gave no reason for their lower score, while the other described that she felt distressed because unlike the young man in the film she would not receive love, acceptance and support from her family if she were to test positive.

*"Level 1, because unlike the people on the films, I don't see my family giving me support I would need when I'm HIV-positive".*

## Responses to the communication tool

Participants were asked if they would show the animations and film to their family and or friends. Overall, young people were enthusiastic about sharing the animations and film with others. The principal reason was to support others who they knew were living with HIV and enable disclosure conversations.

*“Yes, I would show it to my family because they would actually be the most important people I would need if I could be positive, so I’ll show them the APP to get them to understand HIV and the importance of support from families when you are diagnosed - things might be much easier for all of us as a family”.*

*“I would show it to my family because maybe there is someone who is HIV positive and they know nothing”.*

## HIV positive respondents

A total of 12 participants received an HIV positive result and were recruited onto the study.

Each participant completed a further interview after their post-test consultation with the clinic nurse. A hope score was recorded; the intervention was repeated, concluding with a final hope score.

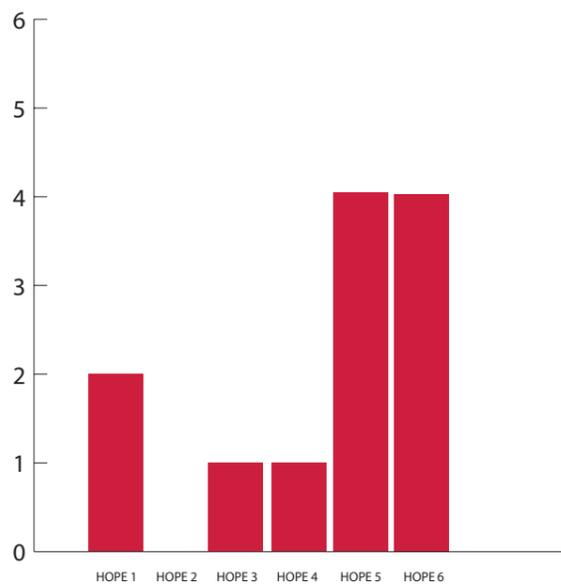


Figure 7. Post HIV test (positives) hope scores

## Post diagnosis hope score

Three participants recorded a hope score of 1, describing how they felt confused, were unsure about what to think, and how they would manage their infection.

*“Right now I am torn apart, my life is in pieces, this means I will have to take care of myself, accept and support myself”.*

The respondent who reported a hope score 4 provided no answer to how they felt about their test result. Three of the five participants who scored a hope level of 5 described how they felt relatively confident about their results, stating that the virus would not change their life and that they would be able to manage HIV with treatment:

*“Because I know I will be perfectly fine and healthy if I stay on my treatment, my life doesn’t have to change because of my status”.*

Two of the four participants who reported a hope score of 6 specifically described how they would receive support from their family and friends. The remaining two did not provide answers to their scores.

## Final hope score

In response to a second exposure to the media, 5 participants reported the same hope scores as their post-test responses, whilst 6 reported higher

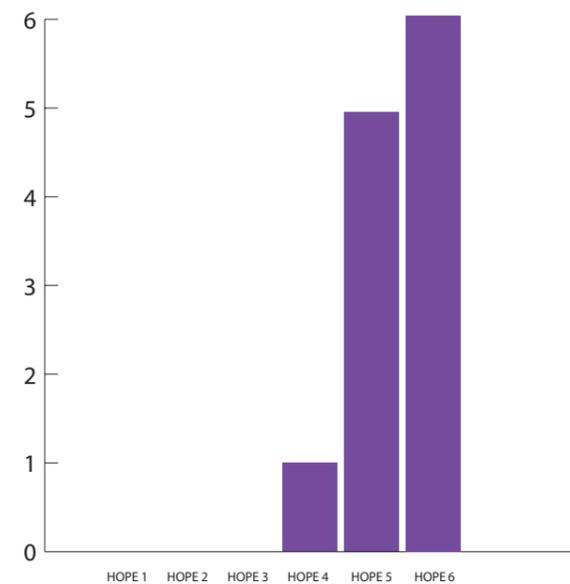
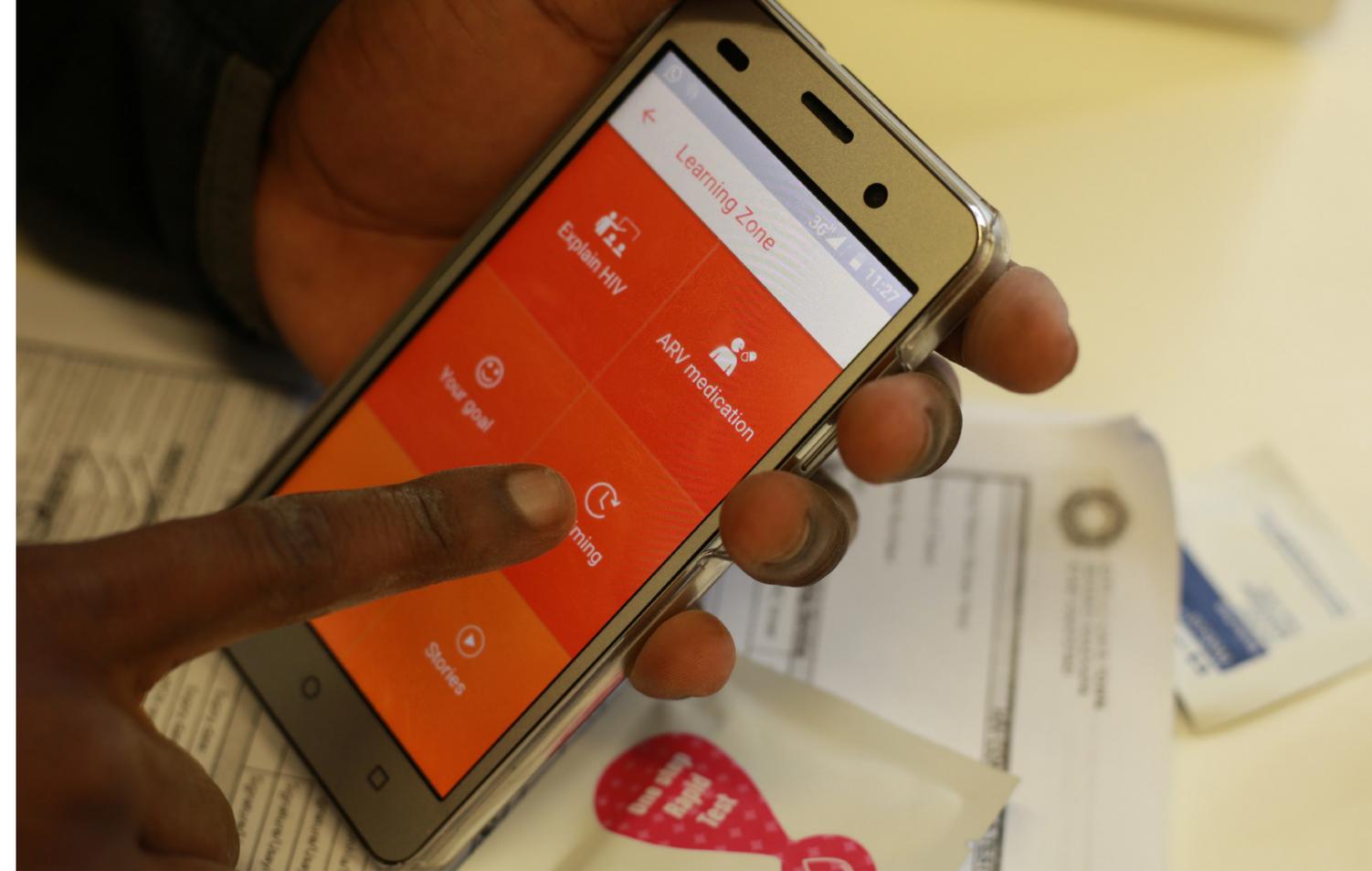


Figure 8. Final post intervention hope scores.



scores. One participant reported a lower hope score. Responses to the media mirrored their earlier contributions, focussing on treatment, gaining support and acceptance and not losing hope:

*“Level 6, Yes, I have learnt that it is important that I take my treatment well to stay healthy”.*

*“Level 6, because I am motivated by the film, I can see that I can indeed live a normal life if I start taking my treatment and accept my situation”.*

However, the participant recorded a lower score after seeing the film again because it reminded her of the reality of testing positive:

*“This is really hard for me, now my level of hope is back to 5, not because I’m losing hope, but because after seeing the film again I realised it’s not a joke.”*

## 3 month follow-up

Follow-up comprised phone calls and WhatsApp. Over the three months, 11 respondents reported that they were taking ART and remained linked to care. The young woman who marked a lower hope score cited above was lost to follow-up.

## Conclusion

Sharing interactive animations that explain the complex bio-medical concepts of HIV infection and treatment along with a film that describes how other young people are successfully living with HIV were effective in increasing young peoples levels of hope pre- and post-diagnosis. Many reported that they had learnt about how HIV and treatment work, improving their confidence that they would be able to manage the disease. The film story motivated young people about gaining support and acceptance from significant others, or at the very least support organisations. Young people were excited about the interactive media and wanted to share the information with their families, friends and communities. 11 of the 12 participants who tested positive reported that they were taking ART and remained linked to care.

## Limitations

This was a relatively small pilot, and thus had various limitations. Self reporting is not the gold standard for validating adherence. Medical records and first stage viral load measures are the best method for confirming adherence. However, due to the limitation of time and budget this was outside of the study’s scope.

# RECOMMENDATIONS

## What do we want to change?

1

**Acknowledge that young people want to experience a different approach to HIV testing.**

Young people find testing difficult, causing them anxiety and worry about how they will manage HIV and what others will think of them if they were to test positive. Many are especially concerned about stigma.

2

**Stop telling - start learning!**

Shift from a didactic (telling) to a learning experience by engaging young people with interactive learning media and hope stories - helping young people to build resilience for the test experience.

3

**Increase young people's resilience for an HIV test**

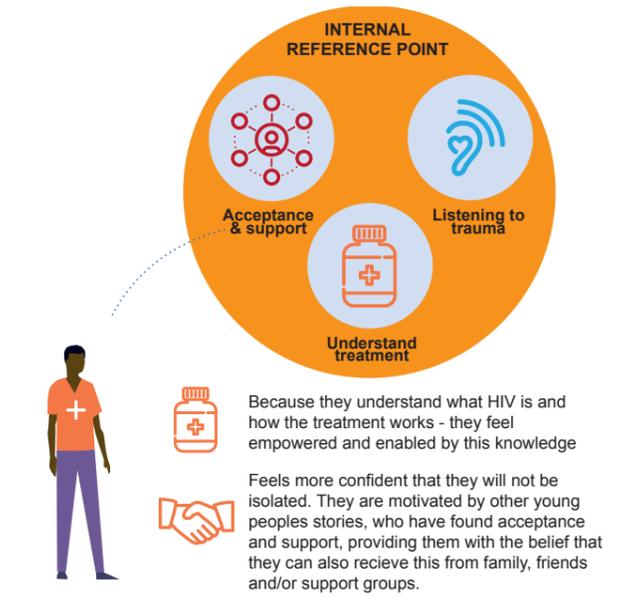
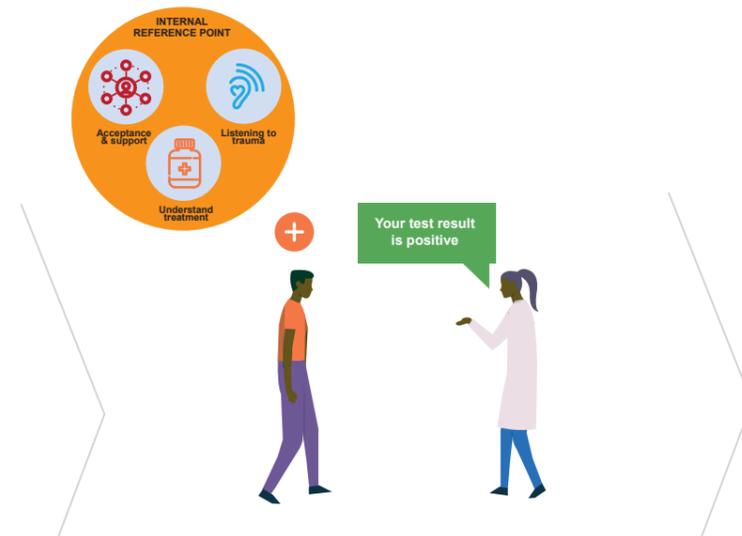
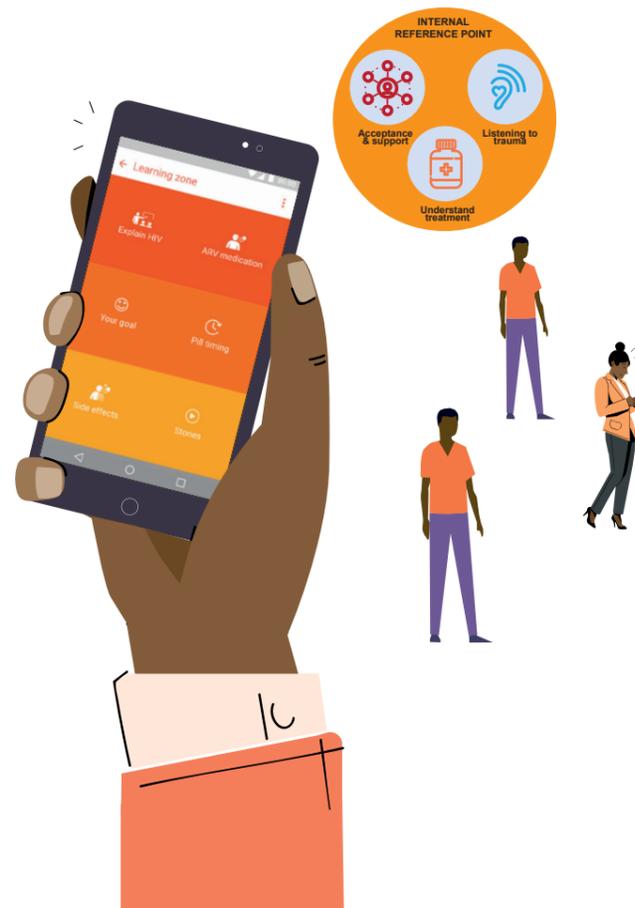
Increase young people's HIV knowledge, especially about how the treatment works, supported by stories of hope. This increases their pre- and post-test resilience, which is essential to improving post-test outcomes.

4

**Increase baseline HIV knowledge across youth community**

Increase HIV knowledge among all young people who visit clinics improves resilience to test regularly, better post-test response and enables them to share the media with others, increasing baseline knowledge throughout their community.

This is also relevant for self-testing  
Self-testing does not change how youth feel before a test - it just changes how and where they test. We still need to engage youth with an interactive learning experience that increases HIV resilience.



**1 The diagnosis**  
Communication

**2 How young people respond**  
Internal communication

**1+2**  
Creates the young person's definition of the situation

**Determines what happens next**

- Knows what to do next - attends the clinic and understands how to take ARV medication properly.



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warren@hdca.co

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