



Salus
Accept • Support • Belong

BREAKING THE SILENCE OF STIGMA

Becoming the communicators in
our community



wellcome
centre
infectious diseases
research in africa

Warren Hickson (PhD) & Aphiwe Mtendeni ©
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Introduction

The Salus Eastern Cape pilot is an evidenced-based HIV communication project informed by two previous phases of research which explored how communication strategies can effectively motivate young people to learn about treatment and support adherence to ART. This research has led to the development of a new approach to HIV communication and engagement which addresses two key challenges that exist within the marginalised communities of South Africa. The first challenge is related to how stigma remains one of the most significant barriers to effective communication and engagement. Stigma prevents individuals, families, friends, and entire communities from talking about HIV. The second challenge is related to understanding. Currently, there remains a dearth of HIV knowledge among community members, resulting in confusion about both the nature of the disease and its treatment.

The Salus approach

The Salus culturally sensitive approach to communication addresses these challenges by engaging with the cultural dynamics that frame and influence how communication occurs within the South African context. These comprise two factors, Ubuntu and the oral tradition of storytelling.

Ubuntu: The importance of belonging

South Africa's indigenous communities are based upon the notion of 'Ubuntu,' where community members have a unique commitment to one another, which includes a shared sense of common life. Ubuntu frames a person as being inseparable from their community. This translates into individuals carefully considering their actions in the context of others. This can be understood as a 'social contract' which impacts an individual's choice/action and may, or may not be constrained by the wider community's pursuit of shared aims. This is an essential factor to consider which impacts the communicative processes that an individual considers as they negotiate the process of becoming motivated to engage with research. Motivation to engagement is, therefore, a 'social construct' that locates the importance of including family and community members into a public engagement strategy that seeks to effectively empower community members to learn, become excited, and be part of the engagement process themselves.

The oral tradition – The importance of storytelling

Storytelling is integral to the oral communicative culture that exists in Africa and is recognised as the main method of knowledge formation and dissemination among many educationalists. The previous research and preceding pilot that informed the design of this project found that community members wanted biomedical information to be communicated through interactive animations and storytelling films that they could repeatedly view and learn from, and share among community members (socialised learning).

The Salus programme:

The Salus programme comprises three stages (designed as modules) of engagement. These have the aim of empowering youth to break free of the fear of HIV stigma, enabling them to talk freely about the disease and its treatment, and to become inquisitive about previous and current research and its relevance to them and their community. Interactive animations and storytelling films (made by community members about community members) were used as tools to facilitate and empower talk, discourse and involvement/dissemination.

Setting:

The pilot was conducted at the KT Mchasa School located in the Umtata Region of Eastern Cape, South Africa.

Ethics:

Permission was granted from the Department of Education and the school Principal to conduct the programme among pupils aged between 14 – 19 years. Approval was also given by the Department of Health to gather baseline data and verify reported outcomes from the school's local HIV clinic.

Evaluation and Monitoring:

A series of questionnaires and data collection forms were used to collect participant information, attendance, smartphone ownership, digital communication activity and samples of content. Interviews were captured using film. Themes determined from interviews were used to inform the final edit of the (story report) film

The Team:

The Salus team was led by Mr. Aphiwe Mtendeni. Aphiwe is from the community and initiated, organised, and delivered the pilot. Dr. Warren Hickson directed the work. Professor Meintjes was the CIDRI advisor.

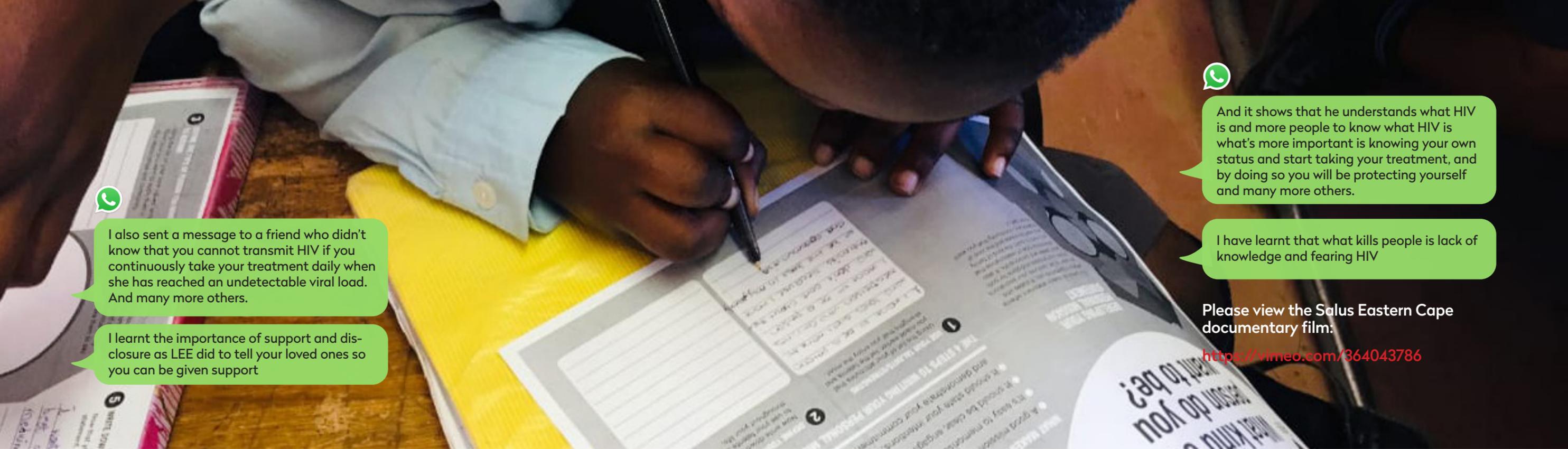


The Salus 'We all belong' tool-kit

The Salus 'We all belong' tool-kit comprises a series of modules that encourages young people to talk about the importance of Ubuntu, and how belonging is a central determinant to an individual, family, and wider community wellbeing. During the sessions, stigma is discussed, being 'framed' as a challenge to our belonging and wellbeing. A core component of this module is to show stories of other young people, who have, post-diagnosis, successfully reconnected to significant others who accepted and supported them, affirming their belonging.

Learners are then encouraged to write and share 'mission statements' within the group, inspiring each other to support and accept one another as a response to HIV.

The tool-kit also aims to increase knowledge about HIV and its treatment, framed as an example of how medical science and research can significantly impact people's lives and communities. Previous research identified interactive animation as the preferred modality for learning among youth. A series of animations were co-designed (using the principles of Human Centred Design). Multi-media learning theory (Mayers 2009)¹ was used to inform development, design, and production.



I also sent a message to a friend who didn't know that you cannot transmit HIV if you continuously take your treatment daily when she has reached an undetectable viral load. And many more others.

I learnt the importance of support and disclosure as LEE did to tell your loved ones so you can be given support



And it shows that he understands what HIV is and more people to know what HIV is what's more important is knowing your own status and start taking your treatment, and by doing so you will be protecting yourself and many more others.

I have learnt that what kills people is lack of knowledge and fearing HIV

Please view the Salus Eastern Cape documentary film:

<https://vimeo.com/364043786>

This theory posits the importance of 'segmenting' visual information that allows users to ask questions, and move back and forth through the information increases learning outcomes. These animations were adapted for use for this pilot.

The tool-kit includes modules that are designed to empower young people to become the communicators within their communities, sharing the knowledge of HIV science to encourage conversation and engagement. Utilising young people's digital communication strategies was key to the success of this stage. Learners were invited to volunteer to become 'SEEDS,' receiving training about how to become a communicator in their community. The aim was to empower them to share the digital assets across their social networks, facilitating talk about HIV, biomedical science related to treatment, and the encouragement to test and access treatment if appropriate.

Video (1:27)

I think this video is amazing it shows us about the person who has accepted their status and someone who is positive who doesn't see himself as a different person

It's not cool to discriminate people living with HIV because they didn't go out there looking for it, so they need support...

Outcomes:

Please view the Salus Eastern Cape Film: <https://vimeo.com/364043786>

Objective 1: To facilitate group discussion about HIV, and to empower learners to encourage discussion within their school and wider community.

As a result of module 1 (which includes showing films and animations), pupils showed high levels of excitement and motivation to talk about HIV science, treatment and to encourage acceptance and support to one another and wider community members. This is evidenced in many of the completed mission statements and classroom discussions evidenced in the project's documentary film.

Objective 2: To increase learning and knowledge about HIV, treatment and how the outcomes of science research changes lives.

The fusion of digital animation and storytelling facilitated discourse among the learners, encouraging openness and a collective learning experience. Multi-media learning theory defines the principle learning outcome as 'meaningful learning', which is evidenced by activity/behaviour. Meaningful learning was demonstrated by many young people saying that they felt 'liberated' from the fear of HIV because they had a new understanding of how the power of science had provided medication that enables people to live normal and long lives (as shown in the film). Some

became excited about becoming researchers themselves, while others showed a keen interest in learning more about current HIV research activity. One exciting outcome of meaningful learning was reported by the DoH, noting a two-fold increase of young people (mainly from the school) attending the clinic for a test, and asking for treatment if required.

Objective 3: To empower youth to become the communicators in their community – becoming the central actors of engagement within their community.

250 learners downloaded Salus content to their smartphones (recorded during the sessions) and

reported sharing that content with members of their WhatsApp groups. It was not possible during this pilot to track how many people chose to view the content, although many participants reported having had WhatsApp discussions about it with friends. However, many young people reported positive engagement about the content with their friends. Based upon feedback across the groups, WhatsApp group dissemination was estimated at approx. 7 - 8,000. Table 1 shows participant information concerning smartphone ownership and the parameters of potential dissemination activity.

Grade	Males	Females	Total	Ages	Smart phone ownership**	How many Smart phones	How many use Whatsapp**** brought to school	Total amount of people in groups*	Average per Whatsapp downloaded	How many downloaded Salus content
8A	64	53	117	15-17	36	26	36	1586	61	26
8B	38	51	89	15-16	37	29	27	913	34	27
9A	34	51	85	15-16	37	30	36	2329	64	36
9B	31	44	75	15-16	17	4	8	209	52	4
11A	13	37	50	16-18	19	17	19	1,008	59	17
11B	42	57	99	16-19	52	37	35	1211	35	35
11C	12	20	32	15-17	15	9	15	1053	85	9
11D	26	34	60	15-17	29	27	26	1538	59	26
11E	16	23	39	15-17	24	6	18	978	54	6
12A	8	19	27	16-19	20	7	18	687	38	7
12B	25	37	62	16-19	34	12	12	1045	87	12
12C	17	31	48	16-19	40	20	28	1387	50	20
Totals	326	457	783	-	360	191	278	13,522	663	225

*Comparing groups showed the overlap of contacts was approximately 15%. This was factored into the total estimate of unique contacts (11,493) across 225 people @ an average of 51 contacts per group. **Mobile phone ownership averaged at 50%, with 58% of phone owners bringing them to school. ***78% of phone owners reported to use Whatsapp, averaging 51 friends per group.

Table 1: Message dissemination data

¹ Mayer, R.E. 2009. Multimedia learning. Cambridge university press.

Learners mission statements:

We need to support each other. We need to put a stop to people discriminating to people who are HIV positive. We need to encourage young people to go for a test; we need to know our status. We need to support each other; we need to love one another because HIV is no longer a killer disease. One can live a long life and be happy with the disease. **It needs us to stand together and say enough is enough.**

Please view the Salus Eastern Cape Film: <https://vimeo.com/364043786>

“LET US LEARN TO KNOW MORE AND JUDGE LESS”

Young male learner

“Forgiving yourself is one of the most powerful keys to happiness. I, as a young person, want to change the world. I want to leave a legacy. If I leave this world, what do I want people to say about me? Would they say I was a giver or a selfish person? I want to change peoples lives. We must support one another. ONE LOVE - ONE HEART. Let’s get together and feel alright. My dream is seeing all mankind living together. You must be the change you want to be!”

“I would like to learn more about HIV positive people so that I can give the information back to my community. A lot of individuals are full of judgement in my community. I would like to change their views about HIV positive people. I would like to see a united and happy world where women and children’s rights are not violated. I would like to live in a better world.”

“HIV positive people think of themselves as different people while they are not! Being different doesn’t mean that you are not human; it means that you have gained wisdom. I want to change the way HIV positive people think of themselves, and make them understand that this was destined to happen, and with their wisdom, they could change lives!”

“ I appreciated it (Salus); it came here to assist us. As I was engaging with the learners, I noticed that the knowledge of HIV and AIDS has increased. Even the Department of Health is saying that the number of learners who are testing in the nearby clinic is increasing; it’s doubled now; that means the work you have done here in the past seven weeks is saving Africa children. We need this, if you can come next time - we need it”.

Mr Khwatsha. Department of Education OR Tamboinland District

Conclusion

Overall the pilot was successful in meeting its core objectives. The provincial Department of Health reported a two-fold increase of young people from the school and local community attending the local clinic for a test, and requesting treatment. Baseline data gathered from the clinic’s previous 12 months statistics confirmed the reported increased activity. This is also confirmed by both the Eastern Cape Department of Health and the Department of Education, who are eager to see the programme scaled across their region.



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warren@hdca.co

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This report is the result of a truly collective effort. We express our sincere gratitude to all the local community members, health care professionals and volunteers in Khayelitsha who participated in the study, especially the many young people who shared their stories and experiences. In addition, particular thanks are due to the Salus team led by Mr Aphiwe Mtendeni.