

USSD Testing Report: Communication sharing practices and needs of people living with HIV: A case of Nkangala in Mpumalanga and Ekurhuleni in Gauteng



TITLE

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A USSD TESTING REPORT PREPARED FOR

Centre for Communications Impact

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List of Abbreviations and Acronyms

AIDS – Acquire Immunodeficiency Syndrome

ART- Antiretroviral Therapy

HIV – Human Immunodeficiency Virus

mHealth - The practice of medicine and public health supported by mobile devices.

PLHIV – People Living with HIV

SMS - Short Message Service

STI – Sexually Transmitted Infections

TAC – Treatment Action Campaign

USSD - Unstructured Supplementary Service Data

1. Introduction

Communication efforts and strategies for ART adherence as reflected in *South Africa's National Strategic Plan on HIV, TB, and STIs 2017-2022* are increasingly being considered as a way of supporting people living with HIV (PLHIV) in South Africa. The National Department of Health (NDoH), *National Trends of STI 2015/16* provides ample research evidence which suggests that non-adherence to treatment continues to be a threat towards achieving positive health outcomes for PLHIV, and that efforts should be made to facilitate adherence. Many of the interventions that have been implemented in other countries to facilitate retention into care and improve adherence focus more on reducing the time PLHIV spend in a health facility and on decongesting overcrowded clinics (Gonzalez-Perez, et al., 2013; Maharaj, et al., 2013). In South Africa, the Centre for Communication Impact (CCI) has identified a communication strategy as an essential tool to improve adherence. A part of this strategy is the purported use of mobile health (Mhealth) in the form of SMS (short message service) messaging. Akter and Ray (2010) define mHealth as the use of mobile communications such as mobile phones, monitoring devices, personal digital assistants (PDAs), and other wireless devices for health services and health information sharing. Some of the uses they cite as common are: creating, storing, retrieving, and transmitting data in real time to improve the quality of patient care.

The use of mHealth has grown significantly in both developed and developing countries (Valenzuela, 2009; WHO, 2011). In countries that are developed, according to WHO (2011), the primary focus of mHealth strategies is to reduce health care costs, optimize assets utilization and efficiency, deliver higher quality of care, and improve patient experience of care. In Sub-Saharan Africa (and other developing regions), these strategies focus on improving access to basic health care, as well as facilitating remote diagnosis, monitoring and prevention activities of healthcare delivery. This also results in improved access to health-related information, enhanced effectiveness of service delivery, and reducing the burden of healthcare delivery undertaken by well-educated health care professionals.

There has been a number of systematic reviews and evaluations of mHealth tools, which have reflected very positively on their accessibility and the extent to which they can have a positive influence on health outcomes (Lim et al, 2008; Chang 2008 and Chib et al. 2012). A wide range

of mHealth services appears to use mobile voice communication such as health call centres, toll-free numbers, and emergency services. Recently, the use of mHealth services providing services such as text messaging is also gaining momentum as a viable treatment support option for people living with chronic diseases. In developing and implementing these messaging platforms, there is a need to pre-test the messages to ensure that they are clear and have the necessary content that would influence the desired health change (Cornelius et al. 2011).

In cognisance of this need for pre-testing, the CCI has undertaken to develop a communication strategy aimed at improving adherence to Anti-retroviral treatment (ART). As part of the communication strategy, the CCI intends to use targeted SMS messages to be sent to PLHIV every week to educate as well as inform PLHIV about certain aspects of HIV and its treatment. It is envisaged that the communication strategy will facilitate engagement between the CCI program and PLHIV as users. Before using these messages CCI, through the Human Sciences Research Council (HSRC) undertook to empirically pre-test these messages for suitability, clarity, and relevance to PLHIV. In this document, we report on the pre-testing process and provide the findings of the activity.

2. The SMS pre-testing methodology

The pretesting methodology adopted a qualitative approach that is holistic, deductive and participatory. A qualitative approach allowed the research team to carry out a comprehensive examination of aspects such as the clarity, content, relevance, and effectiveness of the messages intended to be sent to PLHIV. The methodology also yielded a deeper understanding of participants' reflections on the SMS strategy. It also provided insight on participants' understanding of the information contained in the SMS messages and their perceptions about the extent to which the SMS messages provide new knowledge to the targeted PLHIV. In order to complement the qualitative approach, the pre-testing followed the Principles of Ownership, Control, Access and Possession (OCAP) throughout the process. These principles offer a way by which PLHIV can participate in the research process, particularly in decision-making. The approach was useful in that it made provision for participants to make decisions on the messages to be sent to PLHIV (NAHO, 2007). Building

relationships through trust is considered an important element of this approach (IPHRC, 2004), thus the plenary sessions that were held as an initial session in each of the testing sites were important forums for gaining trust from PLHIV. In each testing site, the Lifestyle messages were tested in a plenary session that involved all participants. This was structured as a testing group discussion in which all the present participants engaged with the researchers and with each other in discussing the messages. These sessions formed an important platform for engagement and afforded the researchers an opportunity to observe the communicative practices of participants (for example, turn domination characteristics) in preparation for the formation of subsequent testing groups. In addition, the researchers adopted a flexible and iterative approach that allowed the participants to share knowledge they already possessed, suggest modification of the SMS messages, and remove SMS messages that they thought were not helpful. In each of the study sites, participation was voluntary, which means that participants had a right to withdraw from participation at any point during the research. Participants were informed of this right prior to commencement of the testing discussions.

Data was collected from PLHIV in Nkangala and Ekurhuleni districts in the Mpumalanga and Gauteng provinces of South Africa respectively. Nkangala is a district in Mpumalanga, a province ranked the third most rural province in South Africa. Nkangala district has a population of 1,121, 839, with an unemployment rate of 28.4%. Ninety percent (90%) of the population is dependent on the state for the provision of all their health services¹. The dominant languages are Siswati and IsiZulu. In Ekurhuleni, in the Gauteng Province the estimated population is 2,865,611². Seventy-seven percent (77.8%) of the Ekurhuleni population are uninsured and rely on the public health services. Latest statistics suggest 450 000 people in the metro are HIV positive and young women in this district have been found to be more vulnerable to HIV and AIDS due to social issues such as poverty. Currently 167 698

¹ <http://www.sajhivmed.org.za/index.php/hivmed/article/view/168/282>

² DHIS 2010 Mid-Year Population Estimates

of them are on ARVs. Of these 7 243 are children under 15.³ The clinic in Ekurhuleni is located in an urban township, where the dominant languages are IsiZulu and Sesotho. The two sites were chosen because they are implementing sites for the CCI mentorship programme and these clinics are the ones that specifically work with the mentorship programme.

Purposive sampling was used to select participants. This is a sampling technique in which the researcher makes a deliberate choice of a participant due to qualities the participant possesses, and the relevance of such qualities to the research question. It is a non-random technique that does not need underlying theories or a set number of participants. Simply put, the researcher decides what needs to be known and sets out to find people who can and are willing to provide the information by virtue of knowledge or experience (Tongco, 2007). In this case, people living openly with HIV were purposively selected. Subsequently snowball sampling, which is the sampling technique of asking a participant to suggest another participant, was used to recruit more participants. This was done to ensure that the selected participants are those who would not feel threatened or intimidated to air their opinions in a group setting. Participants in Nkangala were selected through the assistance of a community member who is living openly with HIV, who had been identified by the CCI mentorship coordinator. This recruiter then invited participants with whom she has previously worked on HIV awareness in the community. In Ekurhuleni, participants were recruited from the Treatment Action Campaign (TAC), which is an organisation that advocates for increased access to treatment, care and support services for people living with HIV and campaigns to reduce new HIV infections⁴.

In Nkangala the testing discussions were held in the CCI offices, while in Ekurhuleni they were held at the clinic site. At both sites the discussions started with the lead researcher explaining the aims of the project and going through the informed consent form with the participants.

³<https://kemp-tonexpress.co.za/68628/nearly-half-a-million-of-ekurhulenis-residents-are-hiv-positive/>

Accessed on 9/01/18

⁴ <http://www.tac.org.za/community/about> accessed on 09/01/2018

After this, participants were asked to sign the informed consent forms allowing the researchers to conduct and audio record the discussion. Since the participants had to spend a long time contributing to these activities, refreshments were provided at each site. The discussions were facilitated by the researchers and they lasted for an average of 1-1.5 hours each. Discussions were held in English which was the language preferred by participants. The lead researcher facilitated the testing groups, encouraging the quieter participants, and managing the more dominant voices to ensure that all participants shared their opinions. The value of discussions in eliciting robust data has been widely acknowledged by many methodology scholars such as Mouton (2008). The discussions were audio-recorded and later transcribed for analysis.

The format of the discussions was similar to 'collaborative yarning' (see Bessarab and Ng'andu, 2010), which creates a space in which participants can feel comfortable and speak freely. The testing group started with 'social yarning' in order to gain trust and rapport (Geia, Hayes and Usher, 2013). Social yarning refers to an informal process by which participants exchange information about themselves and social issues around them such as politics, weather etc. The conversation was then formalized to 'collaborative yarning' which is described as a yarn that occurs between two or more people who are discussing a research topic which may lead to new understandings. The advantage of this testing group format is that it created a forum in which issues such as community attitudes, values and beliefs towards messages (that might not have otherwise been brought to light in a one-to-one interview) arise (Bessarab and Ng'andu, 2010). In addition, a testing group facilitates a chance for the group to deliberate until they reach a consensus or common understanding and speak with one voice.

2.1 Participant characteristics

A total of twenty participants were involved in this study. Eight of these participants were drawn from people living openly with HIV in Nkangala. In Ekurhuleni, 12 participants were drawn from PLHIV from the Treatment Action Campaign (TAC). Nine of the twenty participants were male and eleven (11) were female. The gender balance was intentional in order to ensure that perspectives of both genders are represented. Eighteen of the twenty

participants were unemployed and had no medical aid so they rely on the public health system. Seven of the participants were married and living with a spouse, the remaining thirteen were either single, widowed or in a co-habitation. The female average age was 36, while the male average was 40 in both areas. The criteria of participant selection were:

- Being HIV positive and on treatment
- Willingness to participate in a group discussion
- Willingness to talk publicly about their status

2.2 Details of the testing procedure

The CCI developed a set of 70 messages under three different themes namely Lifestyle, Treatment Initiation, and Adherence. These messages are intended to be sent to PLHIV every week. Under the lifestyle theme there are 10 messages aimed at influencing changes in lifestyle and behaviours; 34 messages are under the treatment initiation theme; and 26 are under the adherence theme. These messages are intended to a part of the USSD M-health platform that will be developed by the CCI.

2.3 Criteria for testing

The criteria for testing was developed by the CCI and it is detailed below.

- **Relevance:** participants' perspectives on how relevant the message is to PLHIV and the extent to which the messages fit in with their life situations. Also considers the extent to which the messages are designed to be understood and to provide support.
- **Effectiveness:** participants' perceptions on how the messages can facilitate adherence or non-adherence.
- **Clarity:** participants' reflections on how easy or difficult was it for them to understand the messages.
- **Chronology:** participants' perspectives on the suitability of the order by which the messages are sent.
- **Message dosage:** participants' perspectives on the frequency of the messages sent i.e. messages sent weekly.

- Gaps: determine if there are any messages participants' feel should be included in the set.

A pre-testing guide that covers all these areas was developed by the HSRC and reviewed by the CCI. This guide was used in engagements held with participants in both testing sites.

2.4 Data collection

During data collection in each testing site, a plenary engagement involving all participants was initially held with participants before they were split into different groups. In the plenary sessions, introductions were done explaining the purpose of the pre-testing and the procedure that will be followed, and getting informed consent from participants. This was done with the aim to break the ice, while at the same time establishing the following:

- Participants' reflections on receiving SMS messages HIV and AIDS treatment on cell-phones, preferred frequency etc.;
- PLHIV perceptions of the benefits of getting the messages;
- Perceived disadvantages of getting the messages.

After the introductions, the *lifestyle theme* messages were tested in the plenary. Participants were given a few minutes to read and internalise all the 10 messages, so that they can give informed feedback about the messages based on the criteria listed above. Then the research team comprised of two senior researchers facilitated the discussion on the 10 messages guided by the testing guide. One of the researchers asked the questions while the other one was recording and taking notes. After this initial discussion, participants were divided into 2 groups (4 people per group in Nkangala, and 6 people per group in Ekurhuleni). One group tested the message under the treatment initiation theme, while the other tested messages under the adherence theme. In testing messages under the initiation and adherence themes, participants were first given a few minutes to read all the messages. Then the facilitator read out the messages in groups of 3 and discussed them with the group, based on the guide. Additional information was collected through field notes written by researchers. In dividing them into groups, care was taken to balance the gender in each group and facilitators were

specifically encouraged to probe perspectives from both male and female participants. The discussions were audio-recorded with the consent of the participants.

2.5 Data analysis

The recordings were transcribed and imported into the Atlati 8 software to be coded. A coding manual was developed initially based on the testing guide and continually revised as the coding process unfolds, adding codes that emerge from the data. The data was then analysed through an analytic framework that integrates content analysis and thematic analysis. The coding procedure allowed for the extraction of pertinent themes and patterns from the data through content analysis. Thematic analysis was further used to interrogate dominant as well as latent themes that emerged from the data, and to therefore draw out interesting issues that emerge from the data.

3. Findings

This section presents the findings of the pre-testing of the messages based on the criteria set out in section 2.3 above. The first part of the section will discuss the general reflections that participants made about an SMS strategy and its perceived value for PLHIV. The sections that follow will present perceptions on the specific messages in each of the three themes namely: Lifestyle, Treatment Initiation and adherence.

3.1 General reflections: perceived advantages and disadvantages of an SMS strategy for HIV and ART adherence

Participants were very positive towards receiving SMS messages on their phones and indicated that it was a very good idea, which has several advantages for PLHIV. The following excerpts show how some of the participants expressed their positivity:

- a) *“when patients go to the clinic for counselling, they just listen and do not ask questions, so using SMS will help us to educate PLHIV like us”* (Male, Nkangala, single)
- b) *“you see these messages have some information we did not know about, so even our family members will gain from them”* (Female, Ekurhuleni, married)
- c) *“Ah this is new (referring to taking medication on an empty stomach)”* (Female, Nkangala, single)

These excerpts reflect some of the positive characterisations of the messages, with words such as *help, gain, and new* used to describe how the messages could be potentially useful. In particular, the view that the SMS messages have the potential to be used for peer education and the fact that they provided new information recurred strongly in the data. Other advantages that were mentioned are that:

- I. Since all of them are PLHIV, the messages would remind them of their responsibility to take treatment when they forget.
- II. Some of them are staying with their loved ones, e.g. parents, guardians etc. who are not infected and are therefore not likely to remind them to take treatment, hence SMS messages would come in handy as a reminder
- III. Some of the SMS messages contained new information for them, which they did not know about before. Examples of such messages that were commonly cited in Nkangala and in Ekurhuleni are:
 - Lifestyle week 9: It is best to eat before you take your ARVs but if you cannot, please take your treatment on an empty stomach. For more info call 0800 012 322
 - Treatment initiation message week 23: Adhere to your ARVs and reduce your risk of getting cancer. HIV weakens your immune system and stops your body from fighting viral infections that can lead to cancer.
- IV. As PLHIV, they perceive the SMS messages as an assurance that they are not alone in the journey and that is comforting in a life situation that makes one feel lonely. As some of them put it:
 - a) *"Being HIV is very confusing....it is nice to keep getting information because it educates you and you don't feel alone"* (Female, Nkangala, married)
 - b) *"I wish someone had thought about this when I was diagnosed. I used to wake up in the morning so confused, not knowing who to ask questions"* (Male Ekurhuleni, single)
- V. SMS messages will be on the phone and would be easy to refer to them again if one needs the information again, as said by a participant:
 - a) *"Sometimes they tell things and we forget, but if it is an SMS it's always on the phone and I can go back and read it again."* (Male, Ekurhuleni, widower)

The messages come at no cost to the user; one does not need to have data to receive the messages so they will be widely accessible.

b) *“These messages are better when they are SMS messages because one does not need data to read them.”* (Male, Nkangala, single)

VI. Some however, mentioned that they would prefer WhatsApp messages for they felt that this is happening in real-time and one can ask questions and get responses immediately, but most were against WhatsApp because it entailed data costs. As one participant put it:

“I prefer them to be WhatsApp messages because then if you don’t understand something you can ask right there...and get an answer immediately” (Male, Nkangala, married)

VII. The messages will also function as a dissemination tool to other members of the family such as children, who need this information on HIV yet parents cannot talk to them about it. The following excerpt exemplifies this opinion:

“This our children like things and we don’t know how to advise them about HIV. Since they always like using our phones, they can easily see the message and learn as well. Or you can just give them the message to read...even these adult relatives you can show them.”
(Female, Ekurhuleni, married)

When reflecting on the disadvantages, most participants noted that they do not see any disadvantages to receiving the messages. However, one participant in Nkangala felt that the messages were too many and they would take up too much of his time. This is how he expressed his sentiments:

“You see, I do a lot of things and reading SMS messages will haayi maan... waste my time”
(Male, Nkangala, single)

Although this sentiment is worth mentioning, it must be reiterated that other participants did not share this view.

3.2 Language

At both testing sites, it emerged that the use of English language in these messages was not preferred. Participants indicated that not all PLHIV understand English, and even those who did, would understand the information better if it is in their language. One female participant noted that:

“...most pamphlets on HIV received at health facilities are in Sepedi, IsiZulu and Setswana, hence the SMS should be in these languages to cater for those that do not understand English language”

After deliberations in both sites participants recommended that efforts be made to use home languages where possible.

3.3 Participants’ perspectives about the messages under each theme

In addition to commenting on the SMS strategy as a whole, participants also reflected on the messages under each theme. The sections below discuss participants’ comments on these themes.

3.3.1 Lifestyle messages

The messages under this theme were aimed at informing participants about healthy lifestyle choices for PLHIV. There were 10 messages under this theme.

- I. *Relevance:* participants in both Nkangala and Ekurhuleni felt that the messages are relevant to PLHIV. Of the 10 messages, participants felt that the messages listed below for were the most relevant because they give hope and encouragement to PLHIV:
 - Week 4: You can stay healthy and enjoy a fulfilling life with your loved ones, even if you have HIV. Talk to your Mentor about living healthily with HIV. For more info call 0800 012 322
 - Week 5: Taking your ARVs can prevent HIV from advancing to AIDS and help you live a healthy life. For more info call 0800 012 322
 - Week 8: ARVs DO NOT affect your sex life in anyway, you can still have fulfilling sex even if you are on ARVs. Always use condoms even if your partner is HIV+

Participants expressed that for PLHIV who have just started the HIV journey it becomes important to know that it is possible to live a fulfilling life with HIV as long as you take the treatment properly. In reflecting on the relevance some of the participants pointed out that;

a) *“Sometimes you feel that you lose hope and you need someone to encourage you... then these messages will give hope to PLHIV”* (Female, Ekurhuleni, single)

b) *“In this life there is a need to be encouraged, otherwise you end up losing hope, then the message takes that part”* (Male, Nkangala, single)

II. *Effectiveness*: participants felt that the messages in this theme would be effective because they address all issues that a PLHIV would like to know in the beginning stages of the HIV diagnosis. For example one participant pointed out that:

a) *“this issue of a carrier is something that many people are still confused about, its good the messages have it”* (Female, Nkangala, married)

Clarity: there was a general perception that most of the messages were clear, although there a few that were difficult to understand. For example, one of the participants noted that:

b) *“I find that the issues are simple and very plain to understand for it is true that doctors prescribe other medications when I am not feeling well”* (Male participant, Nkangala, unemployed)

The above quotation indicates that most messages were understood with clarity. However, there was a perception among the participants in both research sites that some of the messages were not clear and were quite difficult to comprehend as reflected in the following quotes:

c) *“you see a messages on the number of stages confuses those that do not have knowledge about HIV”* (Female, Ekurhuleni, married)

d) *“Ah, what? Taking medication on an empty stomach, the message must just say take medication with lots of water.”* (Female, participant Nkangala)

In general, the message for Week 1, *“there is no such thing as an HIV carrier, however some people do not show symptoms for some time but it is still important to start your ART immediately.”* The participants felt that the concept of an HIV carrier is difficult to understand. It was therefore suggested that a brief explanation of what an HIV carrier is should be included in the message, or be made in a preceding message.

The message for week 3 specifying that there are three stages in the HI Virus, they are Acute HIV Infection, Chronic HIV Infection and AIDS was also identified as confusing. The confusion arose because of the use of the concepts, HI Virus (instead of the commonly used HIV), Acute HIV infection, and Chronic HIV infection. Participants also observed that the information on the stages of the virus are confusing and are not essential to know.

- III. *Chronology:* Participants reflected that when a person tests HIV positive, their sudden interest becomes how the diagnosis is going to affect their daily lives as stated by a male participant below:

“Madam, when you get tested you need to know what comes next you know, you become very anxious about your life” (Male, Nkangala, single)

The idea emerging from the discussions was that messages for week 4 (You can stay healthy and enjoy fulfilling life with your loved ones, even if you have HIV. Talk to your mentor about living healthily with HIV); week 8 (ARVs DO NOT affect your sex life in any way, you can still have fulfilling sex even if you are on ARVs. Always use condoms even if your partner is HIV+) and week 10 (Always practice safe sex, even if you are on ARVs, because there is still a chance of passing HIV on to your partner) should be the first ones. Participants felt that these messages give assurance to the user that one can still have a happy life even when they are HIV positive.

- IV. *Message dosage:* Most participants felt that the weekly messages would work out well because they give the user time to digest the message while they are waiting for the next one. However, it should be noted that as reflected in Section 3.1, one participant felt that

the weekly messages were too frequent and they would take up too much of their time. While this was not a popular sentiment in this testing group, it is noteworthy because it might prevail in the implementation phase among a wider group of people.

e) *Gaps*: For these messages participants felt that more information could be added to the following messages :

- Week 2 – *“There are no specific symptoms of HIV but some of the most common infections include, diarrhoea, TB, weight loss, flu and skin infections”*, as one participant noted:

“uyazi, they must add symptoms like feeling tired. This is what I hear some of our friends talking about everyday” (Female, Ekurhuleni, single)

During the discussions “Feeling tired” was considered as one of the symptoms hence they recommended that it could be added to the symptoms because many PLHIV do not consider it a symptom and do not act on it. It was also stated that messages with content encouraging participants to test even when there are no symptoms need to be added. This was seen as a way to educate the targeted users that it is important to test for HIV even without the symptoms. For example, some participants noted that:

a) *“if we don’t say it, people will wait to see diarrhoea before they go and test, so I think the message must encourage people to test without symptoms”*(Female, Ekurhuleni, single)

b) *“...they have to warn people to not wait for symptoms but to test all the time...”* (Male, Ekurhuleni, single)

Week 8: “ARVs DO NOT affect your sex life in anyway, you can still have fulfilling sex even if you are on ARVs. Always use condoms even if your partner is HIV positive.” In addition to an assurance about a sex life, which was noted as important by participants, there was a consensus that an assurance about childbearing was essential. The following excerpts show how some participants expressed this sentiment:

- a) *“ehee... children as well... we worry about that a lot. The message should say you can still fall pregnant and have babies...”* (Female, Nkangala, single)
- b) *“I think also saying they can still have babies is important”* (Female, Ekurhuleni, married)

The issue that one can also have children even when they are HIV positive came out strongly in Nkangala among male participants. They acknowledged that for most PLHIV diagnosed at a young age this becomes a pressing concern that needs to be addressed in the beginning stages of the HIV journey. There was also a general perception which emerged that more messages should be added to the set addressing issues such as:

- a) *Education on how to use a condom.* This is because there are many people who do not know how to use a condom properly, but they are afraid to ask for guidance or clarity.
- b) *Circumcision and HIV.* There was a general feeling that the value of circumcision is underplayed in many HIV campaigns and it would therefore be ideal to include it. For example”, one male participant noted that:

“...when we were growing up, we were going for circumcision and the practice was viewed as dangerous. Today men are being encouraged to be circumcised, you see things are changing and this is happening in hospitals now” (Male, Ekurhuleni, single)

3.3.2 Treatment Initiation

- I. *Relevance:* participants felt that messages under this theme were mostly relevant to PLHIV. They however pointed that the message for week 8, which reads: *“Check your viral load every six months at your local clinic and make sure that you are on the path to Viral Load Suppression. For more info call 0800 012 322”* no longer applies because viral load testing these days is done after one year, not six months.
- II. *Effectiveness:* while most of the messages were seen as potentially effective and likely to influence treatment initiation, some messages were seen as potentially deterrent.
 - Week 2: Taking ARVs may cause side effects like diarrhoea and nausea. Side effects can last up to 3 months. For help, call 0800 012 322

Participants noted that this message was portraying a very scary side of ARVs. They also expressed disagreement with the fact that side effects take 3 months as most of them had side effects that lasted a few weeks not months. They therefore suggested that the time frame be deleted from the messages

- Week 29: Having HIV means you have a higher chance of getting high blood pressure, diabetes and heart diseases. Eating well, exercising, and being a healthy weight can delay getting these diseases.

This message was seen as very demotivating because it suggest that PLHIV are at risk of all these other infection. A PLHIV receiving this message might feel that there is no use taking ARVs because they are still going to be ill of these other diseases. In particular, participants felt that the use of the word *delay*, suggests that this will definitely happen, although it might be delayed by healthy living. It was generally agreed that this message be deleted. For example, one of the participants expressed it this way:

“what this says is that because you have HIV you will have all these others, I think it scares people....” (Male, Nkangala, married)

- III. *Clarity*: participants felt that all the messages on treatment initiation were sufficiently clear. However, they were concerned with the frequent use of the term viral load suppression and the technicalities of measurement associated with it. They felt that many people knew very little about it and it was suggested that the more common measure of CD4 count be used in the messages.
- IV. *Chronology*: Like in the other themes, participants’ opinions were that it does not matter what chronology the messages came in.
- V. *Message dosage*: The idea of a weekly message was welcome to participants even in this theme.
- VI. *Gaps*: In this case participants had two types of suggestions namely corrections of repeated messages and adding of more messages.

- *Repetitions:* participants noted that some of the messages are repetitive. They suggested that at least one of the repetitions should be removed. The message sets that were identified as repetitive are as follows:

Set One

- Week 3: You should not pay for your ARVs at any government hospital or clinic. You have the right to free ARVs. For more info call 0800 012 322
- Week 17: You have the right to free ARVs and to free health care at any government hospital or clinic. For more info call 0800 012 322
- Week 24: Nobody has the right to sell or charge you for ARVs at any government clinic or hospital. You have the right to free ARVs. For more info call 0800 012 322

Set Two

- Week 7: Viral load suppression is when the virus is reduced to less than 50 copies of HIV per ml of blood. This means your immune system has recovered.
- Week 25: Did you know Viral Load suppression is when there are less than 50 copies of HIV per ml of blood. For more info call 0800 012 322
- Week 30: Viral Load Suppression happens when ARVs are taken every day to reduce the amount of HIV in the body to a point where it is less than 50 copies of HIV per ml of blood

Set Three

- Week 8: Check your viral load every six months at your local clinic and make sure that you are on the path to Viral Load Suppression. For more info call 0800 012 322
- Week 32: Monitoring your viral load is as important as knowing your status. Check your viral load every six months at your local clinic. For more info call 0800 012 322

Set Four

- Week 9: Your body cannot fight and control HIV without ARVs. There is no cure for HIV. For more info call 0800 012 322
- Week 26: Your body needs ARVs to control HIV. Nothing can cure HIV. For more info call 0800 012 322.

Suggested additional information

- Messages which inform PLHIV of their right to ask to be tested for diabetes and blood pressure at the clinic should be added. It was felt that many people are not tested for this and are not aware that they have a right to ask.
- Messages which strengthen the fact that ARVs do not deter one from having a healthy sex life, and that one can still start a family, even while on ART. Participants felt that this is what most people are concerned about and it is therefore an area that needs to be targeted by HIV communication.

3.3.3 Adherence

Messages under this theme are intended to encourage PLHIV to adhere to their treatment. Text messaging was generally viewed as a promising strategy to improve medication adherence by participants.

- I. *Relevance*: *Relevance* of the messages was determined by looking at participants' expectations, needs and their priorities. The participants *felt that* all the messages in this set were relevant to PLHIV. The following excerpts derived from the discussions supports the latter:

- a) *"We are always encouraged to live positively you know when we attend counselling session and eating healthy foods"*(Female, Nkangala, married)
- b) *"Good behaviour is prioritised always and that protection when meeting with a partner is very important"* (Male, Ekurhuleni, cohabiting)
- c) *"Most people we talk to from health facilities always encourage us to take medication in order to reduce other illnesses"* (Female, Nkangala, single)

Participants particularly felt that the messages for Week 2 (*"Live positively, this means accepting your HIV positive status, adhering to your treatment and looking after yourself mentally, physically and spiritually"*); and Week 5 (*"When you adhere to your ARV treatment, there is a very low chance of you getting sick from flu, pneumonia or TB of the lungs"*) were the most relevant under this theme. The messages conveyed information that is already

known to them and possibly to other PLHIV since that information is usually provided by clinicians and counsellors at the clinic. The value of relaying known information, according to these participants, is that it reinforces what they already know and cultivates a strong confidence in the ARVs. In that way it becomes easy for people to adhere to treatment.

II. *Effectiveness: On effectiveness, the aim was to establish the extent to which the messages would address adherence to treatment. These messages were perceived as potentially good in facilitating adherence. As one participant observed:*

a) *“I see that the messages are meant to remind me about what I should always do as a person living with HIV”* (Female participant Nkangala, married)

It emerged that most participants felt that all the messages were potentially effective because they addressed issues that are relevant to PLHIV. An example cited for this was the message for Week 1 (*“Thank you for signing up for the Zenzele program. We will send you regular SMSs to help you with your treatment journey”*) and Week 3 (*“Being HIV positive does not mean that you have to be on a special diet but it is advisable to eat as healthily as possible”*), which participants understood to be reminder messages, which could be used to change presumptive treatment behaviours and improve treatment adherence. Another message that was stated as potentially effective was the one for Week 2 (*“Live positively, this means accepting your HIV positive status, adhering to your treatment and looking after yourself mentally, physically and spiritually”*). This message was viewed as encouraging positive living and does not have negative connotations.

III. *Clarity:* participants felt that all the messages on adherence were clear and easy to read and understand. In particular, they pointed out messages such as those for weeks 1 - 9 as easier to understand than the rest because they present information already known to them.

IV. *Chronology:* when responding to questions about chronology or the order in which the messages come, participants’ opinions were that it does not matter what order the messages came in.

V. *Message dosage:* The idea of a weekly message was welcome to participants

- VI. *Gaps*: The following corrections on specific messages were suggested by participants:
- Week 4: (*“Keep your body as healthy as possible, speak to your counsellor about how to live a healthy lifestyle or for more information call 0800 012 322”*). There was a suggestion to add “nurse and doctor” so that newly diagnosed PLHIV can know that when a counsellor is not available they can speak to other healthcare providers.
 - Week 8: (*“You should store your ARVs in a safe place and out of direct sunlight”*). The phrase safe place might be understood differently by PLHIV who live in informal settlements. Participants suggested that a *safe container* or *tight container* be used instead.
 - Week 9: (*“If you need help with using your pill box, the sister at the clinic will explain how to properly use your pill box”*). Some participants did not know what a pill box is. An explanation was provided by one female participant but there was general agreement that a pill box was not essential since many people do not know it so that message could be deleted.

4. Conclusion

In conclusion, it was apparent that the SMS strategy would be a welcome intervention for PLHIV. In particular, participants felt that the messages would fill the gap of “aleness” that PLHIV often feel after being diagnosed. They also noted that the messages were in most cases written in a straightforward manner and were very clear. However, they suggested that in later stages these kind of interventions should also target the general public because these are people who are still mostly ignorant about HIV, while PLHIV get the education through the healthcare centres.

5. References

- Akter, S., & Ray, P. (2010). mHealth-an ultimate platform to serve the unserved. *Yearb Med Inform*, 2010, 94-100.
- Bessarab D, Ng'andu B. (2010). Yarning about yarning as a legitimate method in indigenous research. *Int Jour of Crit Ind Stud*; 3: 37–50.
- Chib, A., Wilkin, H., & Hoefman, B. (2013). Vulnerabilities in mHealth implementation: a Ugandan HIV/AIDS SMS campaign. *Global health promotion*, 20(1_suppl), 26-32.
- Chib, A., Wilkin, H., Ling, L. X., Hoefman, B., & Van Biejma, H. (2012). You have an important message! Evaluating the effectiveness of a text message HIV/AIDS campaign in Northwest Uganda. *Journal of health communication*, 17(sup1), 146-157.
- Cornelius, J. B., Cato, M., St Lawrence, J., Boyer, C. B., & Lightfoot, M. (2011). Development and pretesting multimedia HIV-prevention text messages for mobile cell-phone delivery. *The Journal of the Association of Nurses in AIDS Care: JANAC*, 22(5), 407.
- Geia LK, Hayes B, Usher K. (2013). Yarning/Aboriginal storytelling: towards an understanding of an Indigenous perspective and its implications for research practice. *Contemp Nurse*; 46: 13–17. [doi:10.5172/conu.2013.46.1.13](https://doi.org/10.5172/conu.2013.46.1.13)
- Gonzalez-Perez J et al. (2013). Rural Uganda: above 50% retention after 10 years on ART. 17th International Conference on AIDS and STIs in Africa, Cape Town, 2013, abstract ADS056.
- Kumar, D., & Arya, M. (2015). mHealth is an innovative approach to address health literacy and improve patient-physician communication—an HIV testing exemplar. *Journal of mobile technology in medicine*, 4(1), 25.
- Lim, M. S., Hocking, J. S., Hellard, M. E., & Aitken, C. K. (2008). SMS STI: a review of the uses of mobile phone text messaging in sexual health. *International journal of STD & AIDS*, 19(5), 287-290.
- Maharaj T et al. (2013). Strategies to address clinic waiting time and retention in care; lessons from a large ART center in South Africa. 17th International Conference on AIDS and STIs in Africa, Cape Town, abstract ADS058.
- Suwamaru, J. K. (2012). An SMS-based HIV/AIDS education and awareness model for rural areas in Papua New Guinea. *Stud Health Technol Inform*, 182, 161-9.

- Valenzuela, J. I et al. (2009). Health care workers' perception of the Internet and mobile technologies in Colombia. *Pan American Journal of Public Health*, 25(4): 367–374.
- Willis E, Pearce M, Jenkin T. (2005). Adapting Testing group methods to fit aboriginal community-based research. *Qual Res* 2005; 5:112–23.
- World Health Organisation (WHO). (2011). Telemedicine – opportunities and developments in Member States. Geneva. (<http://www.who.int/goe/publications>)