



**160 Characters\_**

**Findings Report**





**160 Characters is a collaboration between the SHM Foundation, and UCL's Institute for Global Health**



# Introduction\_

**The 160 Characters Project aims to develop a participatory, interdisciplinary methodology for evaluating and scaling-up the 'Khuluma' intervention that provides peer-to-peer psychosocial support groups via text message to adolescents living with HIV (ALWHIV) in South Africa.**

In adolescents, aged 10 to 19 years old, HIV is the leading cause of death in Africa and the second leading cause of death of adolescents globally.<sup>1</sup> **ALWHIV are at increased risk of mental health problems,**<sup>2</sup> which can in turn lead to poor health outcomes such as poor medical adherence. Given the large number of adolescents living with HIV and the 50% increase in adolescent HIV-related deaths between 2005 and 2012,<sup>3</sup> there is an urgent need to:

- Understand the barriers to accessing HIV services and adhering to Anti-Retroviral Treatment (ART) for ALWHIV;
- Understand the mental health and wellbeing needs of adolescents living with HIV;

- To develop approaches to provide ongoing support that is immediate and accessible to all HIV positive adolescents; and,
- To innovate interdisciplinary, participatory methods for evaluating these complex interventions where adolescents are at the centre of the research cycle.

The SHM Foundation has developed **a promising solution in the Khuluma model** – a psychosocial support intervention that provides closed, peer-to-peer support groups to ALWHIV via text message. Launched in 2013, **Khuluma has supported 160 adolescents in Cape Town and Pretoria, generated more than 60,000 text messages,** and recorded increased social support and self-reported medical adherence, and decreased internalised stigma.<sup>4</sup>

The team has used a mixed-methods approach to analysing this data; from manual coding methods to the use of LWIC software.

It is clear that linguistic and socio-cultural methods are important in picking up on the nuances of the message data; however the sheer volume of messages necessitate the use of 'big data' methods. Hence, the 160 Characters Project brings together the interdisciplinary **insights of adolescent service users, medical science, social science, implementation science, literature, and technology** to 'crack' the Khuluma text message data.

The project is a collaboration between the *SHM Foundation*, and *UCL's Institute for Global Health* with participation from the *Desmond Tutu HIV Foundation*, *STEMA*, *Superbeing Labs* and *Rocket.Chat*.

It is led by a core research team based in London including *Dr Geordan Shannon*, *Anna Kydd* and *Nikita Simpson*; who are supported by an interdisciplinary board of advisors including *Chair, Prof. Maurice Biriotti*, *Prof. Sarah Fidler*, *Prof. Linda-Gail Bekker*, *Prof. Susanne Kord*, and *Ursule Kajokaite*.

Insights from *STEMA* have come from *Des Tan*, *Hector Durham*, *Mikaela Patrick* and *Nicole Minckas*. Insights from *Rocket.Chat* have come from *Isabella Russell*.

Insights from the wider *SHM* team have come from *Esmé Nicholson*, *Cassandra Greenberg* and *Yasmine Uddin*.

However, at the core of the project is the participatory voice of Khuluma's adolescent peer mentors – particularly *Desmond*, *Andani* and *Given*, who are supported by a South African research team including *Malebo Ngobeni*, *Tebogo Konkobe* and *Dr Millicent Atujuna*.

Illustration for the project, and in this report, is by *Maggie Li*.

160 Characters has been funded by the *Small Grant scheme* from *UCL Grand Challenges Adolescent Lives*.

The team would like to thank all those who have participated in the 160 Characters workshops, and the participants who bring the Khuluma data to life.

# Background\_

## Adolescents living with HIV aren't accessing services or adhering to their medication

In recent years, AIDS has become the leading cause of death among adolescents in Africa. In 2015, **adolescents accounted for 37% of new HIV infections**, with young women aged 15-24 years having the highest HIV incidence rates globally.<sup>5,6</sup>

In South Africa, over **15% of young women and 5% of young men aged 15-24 are infected with HIV**.<sup>6</sup> ART has dramatically improved survival, and can significantly reduce the risk of onward transmission.<sup>7</sup>

However, the proportion of ALWHIV on ART is much lower than the South African population average.<sup>8</sup>

## Adolescents living with HIV don't get the support they need

Adolescence and early adulthood are critical periods in the development of mental disorders; it is estimated that **75% of all mental illness emerges before the age of 25**.<sup>12</sup>

ALWHIV are at increased risk of mental health problems, with psychological stressors of the negative side effects of ART, stigma, fear of rejection or being perceived as different, the absence of symptoms, anxiety around morbidity and mortality, and poor patient-provider communication.<sup>13</sup>

Poor mental health has been proven to decrease adherence to ART.<sup>15</sup> Despite biomedical advancements in treatment, psychosocial needs of ALWHIV are not adequately addressed.<sup>16</sup>

There is not a culture of using mental health services in Sub-Saharan Africa, meaning that often **ALWHIV have no one to whom they can talk**.<sup>15</sup>

## Digital Social Support Groups offer a solution

**The World Health Organisation<sup>18</sup> recommends treating common mental disorders such as depression with basic psychosocial support.** Support group therapy has proven an effective means for reducing stigma, and improving both mental health and ART adherence outcomes in Low and Middle Income Countries (LMICs).<sup>19</sup>

However, **psychosocial treatment, including support group therapies, are restricted in these settings**.<sup>20</sup> When they do exist there are many barriers to attendance including lack of knowledge, time constraints, lack of transport, stigma and discrimination.<sup>21</sup>

**Digital support groups are a feasible alternative.** Online peer-to-peer communication is popular among young people and may improve mental health by providing social support.<sup>23,24</sup> They are effective in high resource settings,<sup>22</sup> but have not yet been studied in LMICs.

Texting requires different mental and social processes than face to face or voice,<sup>25</sup> and **it is less formal and obtrusive than other written modes of psychosocial support**.<sup>26</sup>

Scholars have developed a number of text-based methods of analysis, largely using qualitative methods, to analyse online social support groups, including thematic analysis, sociological coding analysis, conversational analysis, and digital ethnographic methods for understanding online and text based community building.<sup>27,28</sup>

**However, there is a lack of consensus as to what is different about online support group interactions, how online communities are built, and how this might be leveraged to benefit mental health**.<sup>29</sup>

# The Solution\_

## Project Khuluma

Khuluma is a **mobile phone support initiative** to address the mental health and wellbeing needs of HIV positive adolescents in South Africa. The Khuluma platform leverages the **power of small groups** to facilitate interactive, closed support groups.

The 'Khuluma' model delivers psychosocial support to ALWHIV in South Africa through closed peer-to-peer support groups of 10-15 participants via text message. Mixed-gender groups are managed by a trained facilitator, and mentors.

Khuluma Mentors are ex-participants who are trained and employed to provide psychosocial support to their peers. Khuluma is peer-led, meaning participants can give and receive advice in a safe, anonymous and moderated space.

Since 2013, the Foundation has worked with **over 160 adolescents** in Pretoria and Cape Town, generated **over 60 000 messages**, and built strong partnerships with universities, technical companies and non-governmental organisations in South Africa.

### How does Khuluma work?



Adolescents are recruited at different clinics



They are then assigned a support group with 10 -15 other members and a facilitator



The support groups run for three months



Participants discuss topics, such medication, relationships, sexual health, school



Guest speakers such as a doctor, nutritionist, psychologist or careers advisor join the talk



Adolescents meet in person and find ways to continue to stay in touch

# The Opportunity\_ *Khuluma Data*

Khuluma participants each send, on average, **6 messages per day** sometimes discussing their hopes, dreams and fears; but also sometimes just checking in and saying hello.

The **60 000+ text messages** generated by The Khuluma text message corpus is the closest we can come to accessing what adolescents are saying to each other in private spaces within ethical constraints, in order **to better understand their experience of living with HIV and their mental health.**

Understanding these mental health needs has the potential to design more appropriate interventions and policies for adolescent populations.

**The 160 Characters Project aims to develop an interdisciplinary arts, health and humanities methodology for understanding the attitudes of adolescents towards their own health via the analysis of text data captured by a peer-to-peer mobile phone psychosocial support group intervention; and, subsequently, to develop strategies, techniques and solutions to serve their needs.**





# Our Methodology\_

## *The Six Voices Framework*

The project began at a workshop in 2017 hosted by the SHM Foundation, and UCL Institute for Global Health, where we asked: can we create a different way of looking at the Khuluma text messages? The outcome of this workshop was the realisation that no one methodology is enough to analyse the data and the development of the

'six voices' framework. Each of these 'six voices' represents a member of the research team, who bring together the insights of **adolescent service users, medical sciences, literature, social science, implementation science**, and **technology** to develop a participatory, inter-disciplinary methodology.

### The six voices represent:



#### Service Users\_

The participatory perspective of adolescents themselves who are living with HIV and have participated in Project Khuluma.

#### Medical Science\_

The clinical and epidemiological voice of healthcare professionals and clinicians allowing us to understand the aetiology of HIV and its co-morbid mental health issues.



#### Literature\_

The linguistic and literary voice of academics who are able to conduct a close textual reading of text message data.

#### Socio-Cultural\_

The ethnographic voice of anthropologists who are able to contextualise adolescent experiences and text message data in contemporary culture and history.



#### Implementors\_

The voice of community healthcare workers, program managers and evaluators who can speak to the practical aspects of the programme

#### Technology\_

The voice of those who will be developing future Khuluma technology, who can speak to programming and specifics of the model



# Our Process\_

In 2018, facilitated by the UCL Adolescent Lives Grand Challenges Grant, we refined the Six Voices Framework, which represents a world-first contribution to HIV and mental health research in LMICs.

## The London Workshop

In preparation for this workshop, we asked the 18 workshop participants to take a look at two extracts of data; one randomly chosen extract of one page; and one set of data generated over the course of a three months support group.

We asked participants to reflect on how they would approach the data from their disciplinary perspective; and what they thought constituted an effective interaction.

We conducted individual interviews with each of the participants; and analysed the results, before presenting them back in a workshop.

## The Pretoria Workshop

The purpose of our Pretoria Workshop was to collaborate with Khuluma's adolescent Peer Mentors to understand what they think works best, and why, and to hear their ideas about how we can make a better service in the future.

The two day workshop involved short individual presentations about who participants are and where they see themselves in Khuluma, acting out their visions and hopes for Khuluma in the future using their career aspirations/interests, a craft workshop of the adolescents' ideal future Khuluma, and an in-depth analysis of text message data.



The workshop included 10 Peer Mentors and two Pretoria-based project coordinators.

The Peer Mentors identified the main purpose of the Khuluma project as being three-fold.

First Khuluma was seen as a support, a home, a place of belonging, and a group that fostered acceptance.

Second, Khuluma was important for education, and balanced medical information against social activities and fun topics.

Third, Khuluma fostered respect, by facilitating an environment that valued the individual, their thoughts and fears, and a space where their opinions were listened to.

In the words on one Peer Mentor, the most important aspect of Khuluma is that it promotes self confidence: "self confidence leads to self-management."

Much of the value of Khuluma was not derived from HIV-focused or medical care. Khuluma groups were seen to provide respect, value, reasons for taking meds, social support and education.

It was perceived as different to medical discourse, which some participants thought was too focused on fear (this meant that some felt they were going to die, and so thought: so what's the point of taking meds?). The current medical system often made them feel small in front of doctors.

Through Khuluma, they found that a sense of hope and positive role models was what makes people want to comply with medical treatment. The Peer Mentors were extremely motivated to expand Khuluma and help others.



# Approaches to the Text\_

Analysis showed that the different ‘voices’ took different approaches to the text:

- Literature is interested in how communication doesn’t work more than how it works; the comic events that lead to resolution, or the tragic events that lead to miscommunication.
- Medical Science is interested in the hard end points like change to immunological states, these correlate with soft end points like self-reported adherence.
- Social Scientists look at the individual voices and how they contribute to and are shaped by broader social issues, they think about how best to build social dynamics so as to meet, often measurable, outcomes.
- Technologists who focus on design look at how we might replicate effective interactions in real life through technology; mathematicians take a naïve approach and build systems from the data based on mathematical language.
- Implementation Scientists think about where this intervention fits into the health system, what does it provide that other services don’t?
- Participants see the potential to change attitudes toward HIV through sharing personal experiences and building self-confidence.

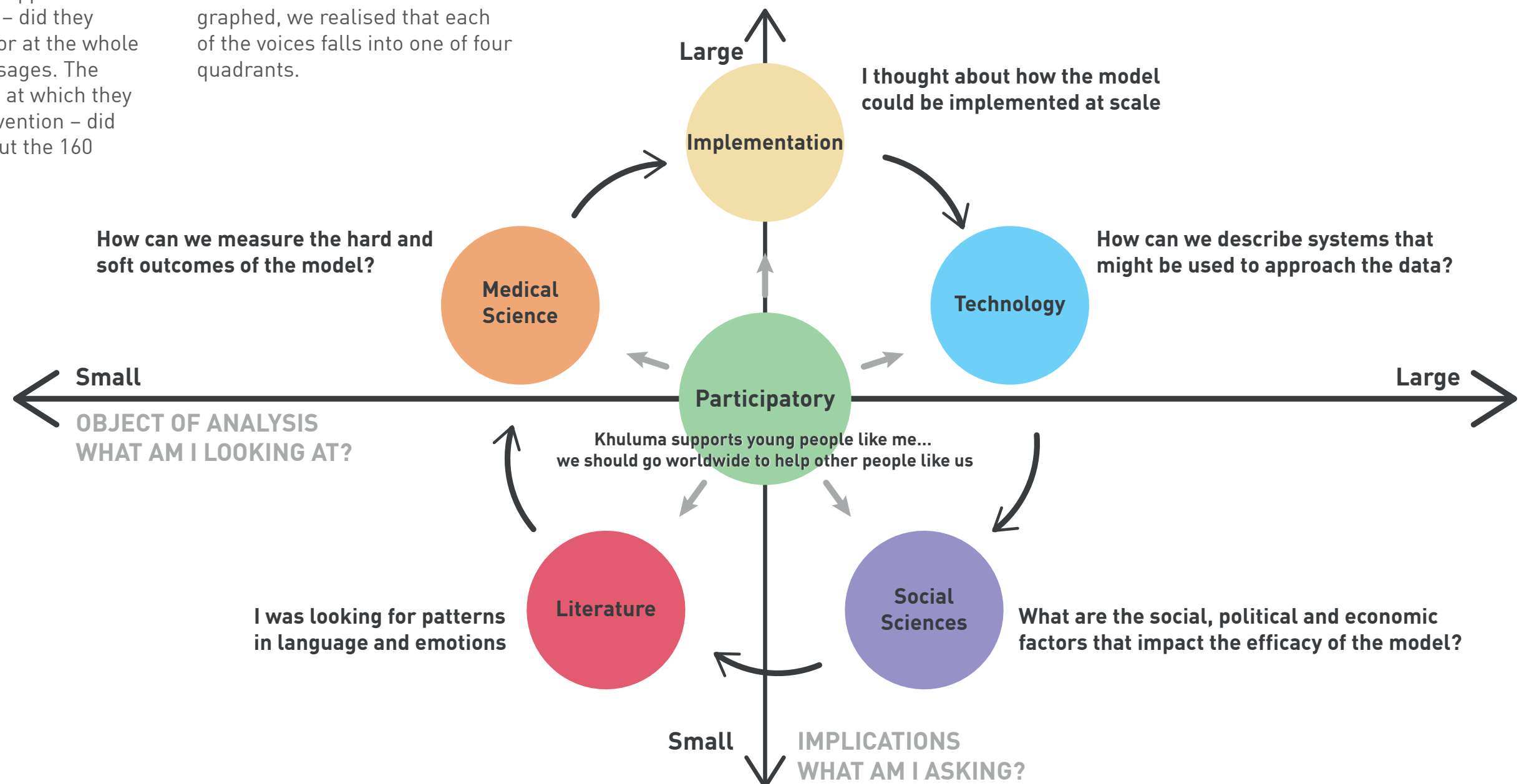
*Indeed, they asked different questions of the text; that were somewhat complementary.*

Social Science	<b>Community Building</b> How do you leverage communities to improve mental health?	<b>Context</b> What are the social, political and economic factors that impact the efficacy of the model?
Technology	<b>Product Design</b> What is the ideal outcome of the model, and how can we get there?	<b>Mathematics</b> How can we describe systems that might be used to approach the data?
Participatory	<b>Insights</b> What worked or didn’t work for you about Khuluma?	<b>Participatory Design</b> How would Khuluma evolve to suit your needs?
Implementation	<b>Behaviour Change</b> How do you get people to change what they do?	<b>Infrastructure</b> What are the resources and technical expertise required to scale the model?
Medical Science	<b>Evaluation</b> How can we measure the hard and soft outcomes of the model?	<b>Review</b> What can we learn from past research as we design for the future?
Literature	<b>Language</b> What do patterns of language indicate about effective support?	<b>Dialogue</b> How and why do certain social dynamics evolve, and which ones are effective?

## Approaches to the Text\_ Continued

We realised that the different voices approached the text on two different scales. The first is the scale at which they approached the actual data set – did they look at an extract, or at the whole corpus of text messages. The second is the scale at which they assessed the intervention – did they think only about the 160

Khuluma participants, or did they think about the applicability to adolescents all over the world. When these two scales are graphed, we realised that each of the voices falls into one of four quadrants.



# Thematic Analysis\_

Analysis showed that there are five key thematic concerns that arose when workshop participants analysed the data. These include self & identity; relationships & responsibility; community & acknowledgement; society & influences; and HIV. Insights from each of these thematic areas were summarised and visually presented in tables. These tables were analysed by both the workshop participants and an independent analyst.

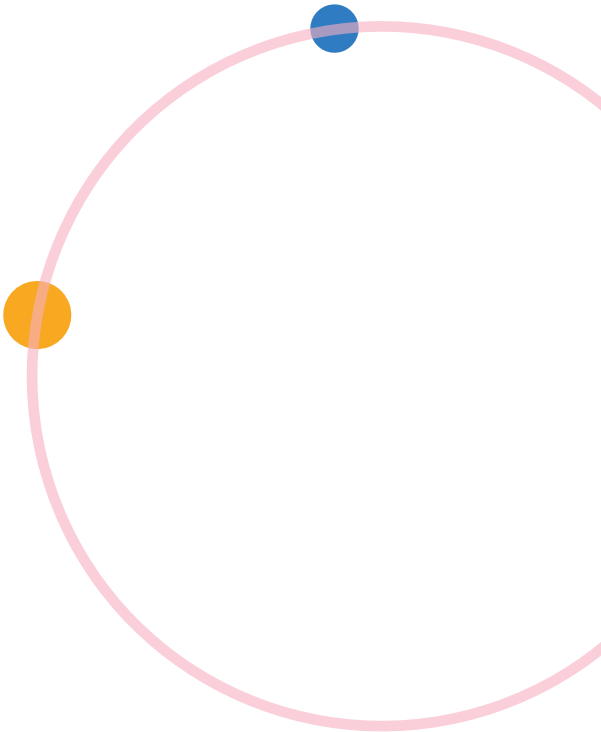
# Thematic Analysis\_

## Self & Identity

Social Science	Individuals can pose their problems to the group to collectively problem solve	Its like in the groups they have an alternate subjectivity or sense of self
Technology	Its great they're talking about hopes and dreams, but sometimes it feels utopian, giving them false hope	Sometimes I think it would be useful if they had a change to be more slow and thoughtful in their responses
Participatory	We are in a relationship to ourselves and must communicate to ourselves	Honesty and self acceptance mean increased confidence to be ourselves, and to reveal our HIV status.
Implementation	No matter how many adherence clubs we have, there will always be a moment where these kids are alone. This group is in the right place at the right time.	Its like being a 'mystery shopper' reading this data, providing the kinds of insights we can't get elsewhere
Medical Science	What does 'well' mean for these adolescents, physically and emotionally?	The text messages are an unsolicited source of data on what they think is important
Literature	There is a lot of maschismo, tough guy speak, in contrast to the weakness of their disease	They seem to be on the way to an authentic voice, but there is a lot that is said that is inauthentic and just repeated

## Insights

- Support groups provide ALWHIV will an alternative space where they can make meaningful connections with other who face the same problems as they do.
- The groups work best when participants are sharing experiences, rather than when a direct question related to HIV is posed.
- It is precisely the fact that these groups are removed from the anxiety and stigma of their relationships and day to day interactions inflected by their status, that makes this a space where they can explore new identities.



# Thematic Analysis\_

## Continued

### Relationships & Responsibility

Social Science	It would be easier for them to build relationships if the group was as homogenous as possible	Participants make 'bids' to the group to be acknowledged or recognised
Technology	Little phrases are really important in the process of building relationships and acknowledging one another	Participants feel that have the responsibility to respond, relate and show empathy – often in the form of a shared experience or statement rather than specific follow up
Participatory	Empathy is important, we don't want other to feel the same pain as we did	Being listened to and responded to is important, to trust in the group and in yourself.
Implementation	The participants can easily convince eachother to do things, even though they don't know eachother well	There seems to be a base level of trust in the group
Medical Science	We can learn a lot from how conversations evolve, in content, emotional ties, comradery and care	In hospitals, they're always getting shouted. These are different kinds of relationships
Literature	They build relationships by checking in on eachother	There is a lot of fear about not having good relationships in the future

### Insights

- Very quickly after the groups launch, it is clear that participants build a set of unsaid rules of communication that underpin the relationships they form with eachother. These relationships are built through 'checking in', comradery and care such that participants are 'acknowledged' in a particular way.
- Participants also police eachother's behaviour, such that when someone fails to respond, incites conflict or does not display empathy, other participants are critical.
- Conversations are not directly effective, meaning they are not always a specific dialogue related to a topic brought up by the facilitator; sometimes conversations even get stuck and seem to be ineffective. However, the 'swirling' of the conversation, or numerous miscommunications, are important to the eventual resolution of issues or collective problem solving.
- Some participants have indicated that simply reading the conversation and having the option to participate is sufficient to increasing feelings of support and decreasing feelings of stigma. One participant indicated this is analogous to the fact that sometimes you go to a café to meet someone, and other times you go just to hear others talking.



# Thematic Analysis\_

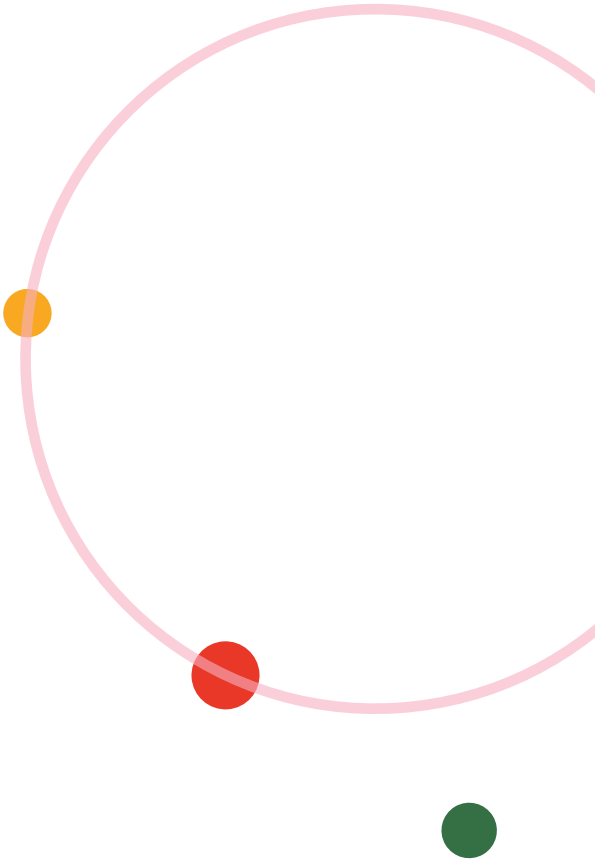
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### Community & Acknowledgement

Social Science	Its useful to think about other kinds of communities these adolescents participate in and how this contrasts	This space is bigger than the sum of its parts
Technology	Lack of physical presence is a double edged sword, they can speak about whatever they want because its anonymous, but there is no guarantee of acknowledgement	The use of nicknames adds the sense that you're not talking to real people, there aren't the same consequences as real life
Participatory	Khuluma will forever be my home, I have a sense of belonging, and belonging is being acknowledged	Its good because it is positive and future focused, not motivated through fear
Implementation	Because this space is anonymous, participants can air issues they wouldn't otherwise discuss	The community is similar – there is comfort in that whoever is here is like me and with me
Medical Science	The content of the groups isn't often about HIV, adolescents don't have to talk about HIV to feel supported	Physical support groups are burdensome, this medium is a good alternative, but can it create the same sense of community?
Literature	Its clear from the heartbreaking conversations that they don't have support from anywhere else, but I worry that this group isn't enough	I think they're behind the curve in their use of social media as a community

### Insights

- This community is unique because it is an HIV related space that is positive and future focused, compared to spaces that are inflected with fear.
- The use of nicknames adds the sense that the space is removed from 'real life' and doesn't have the same consequences, allowing participants to be experimental in their interactions and share more than what they might do when interacting face to face.
- The lack of physical presence is a double-edged sword, in the sense that, though they are able to express what they feel like because it is anonymous, there is no guarantee that someone will reply or acknowledge their expression. By contrast, face to face interaction is not purely verbal but contains infinite gestures and non-verbal cues that act as forms of acknowledgement.



# Thematic Analysis\_

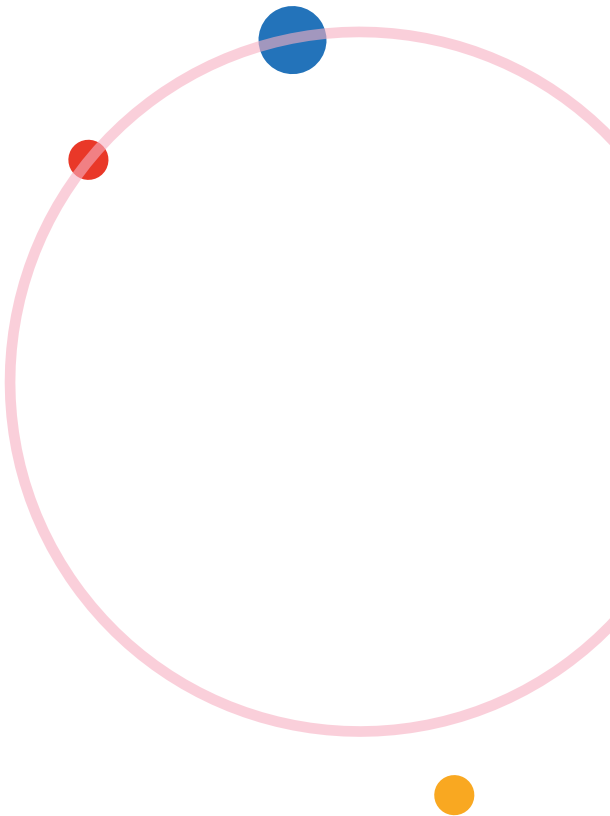
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### Society & Influences

Social Science	Attending to mental health and wellbeing is usually secondary in South African society	At home, adolescents also don't always get the support they need
Technology	There is a lot about the 'vibes' they get from society – both positive and negative	We can compare these conversations to other conversations in society to work out what is unique about Khuluma
Participatory	You are the master of your virus, it should not control you. HIV doesn't define who you are and we can do the same things as HIV negative people	Its important to do community service beyond people living with HIV like in hospitals and orphanages
Implementation	This shows how much social stigma is internalised by adolescents	Doctors can't take responsibility for this dimension of living with HIV, so adolescents don't get enough support
Medical Science	Adolescents are left behind in the development of health policy	How do we best reach adolescents – "edutainment"
Literature	They are very influenced by the church, a lot of the phrases sound like they're straight from a sermon	I would like to know more about how their language is formed, from what societal media

### Insights

- The language adolescents use in the groups is shaped by the communities they participate in. This indicates the extent to which social stigma is internalised by the adolescents.
- The discourse built within the groups is constructed to counter these negative feelings of stigma. Indeed, participants make bold assertions about how they value themselves beyond their status, about their capacities, abilities and place within society.



# Thematic Analysis\_

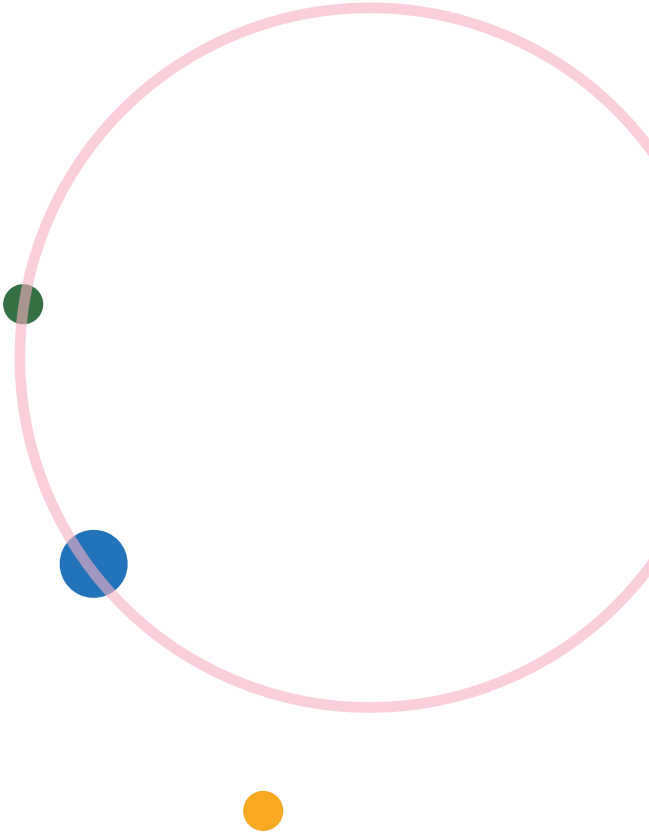
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### HIV

Social Science	The focus on HIV and the outcomes associated with it are not well defined in the groups	The link between social support, self esteem, adherence behaviour and healthy adolescents is clear
Technology	They seem convinced that their lives will change if they take their medication	Participants associated weakness, foolishness and stupidity with HIV and medication
Participatory	You should choose how to live, life is not different to those with HIV negative people	Normalizing HIV, we are normal people living normal life
Implementation	Attending to the mental health and wellbeing of adolescents living with HIV is not done at all elsewhere	There seems to be a trade off between HIV Knowledge and Support. But do adolescents even care about HIV knowledge?
Medical Science	I'm surprised at how little they mention HIV	Even if the conversation does not even mention HIV, is this still an effective means of interaction and support?
Literature	They don't talk much about HIV. Relationships is the most important topic	Their conversations about HIV/AIDS seem quite self contradictory

### Insights

- Adolescents don't bring up HIV directly very often, of their own volition. When facilitators ask direct questions about HIV and HIV knowledge, participants aren't as engaged as when they are discussing other topics.
- Conversations directly about HIV tend to be less effective and incite less engagement than other topics such as relationships, sex, alcohol and nutrition.
- The stigma of living with HIV manifests in all interactions, but speaking about the issues associated with it without speaking directly allows adolescents to have a new attitude toward the virus.



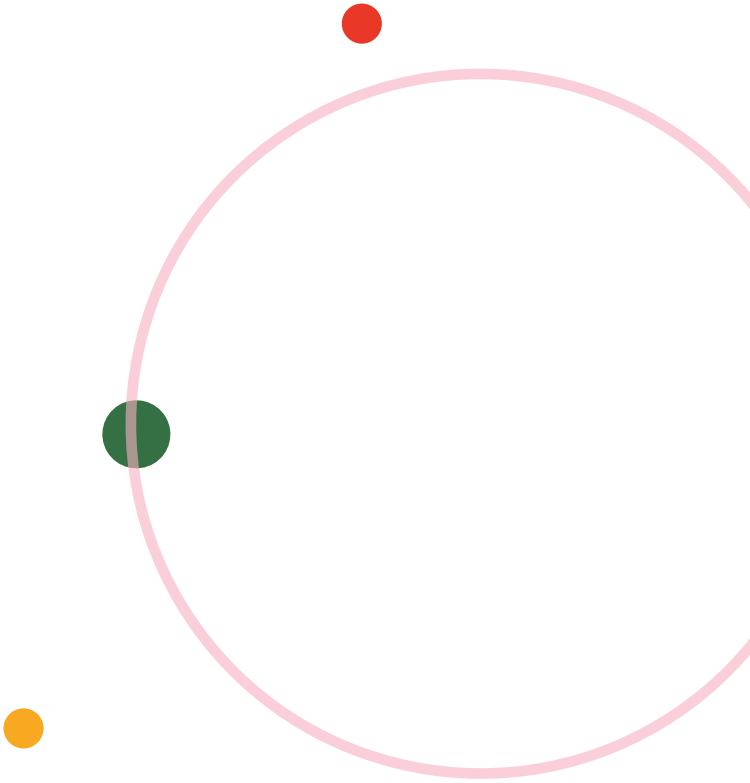
# Thematic Analysis\_

## Continued

### Understanding Effectiveness

Social Science	Attending to mental health and wellbeing is usually secondary in South African society	At home, adolescents also don't always get the support they need
Technology	There is a lot about the 'vibes' they get from society – both positive and negative	We can compare these conversations to other conversations in society to work out what is unique about Khuluma
Participatory	You are the master of your virus, it should not control you. HIV doesn't define who you are and we can do the same things as HIV negative people	Its important to do community service beyond people living with HIV like in hospitals and orphanages
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There were a number of suggestions as to what constitutes an effective interaction in the Khuluma groups; and on how the Khuluma model could be improved. Notably, the voices agreed that adolescents are quick to form their own language, and understand the 'rules' of social interaction that govern the groups. They also noted that peer mentors are better at facilitating than facilitators themselves.



# Thematic Analysis\_

The adolescent-led text message analysis identified the following:

## 1. Effective text interactions involved:

- Clear facilitation/facilitators, ground rules
- Humour: sense of sympathy and belonging
- Participants drawn-in by interesting topic and dynamic group

## 2. Ineffective text interactions involved:

- Mixture of SMS/slang/non-English - difficult for participants to understand
- Threats, negativity, rudeness
- Less active facilitation/facilitator
- Interrupting, not responding to questions

## 3. Topics that work included:

- Sex, events, leisure activities/interests, TV
- Future-oriented: "what do you want to be when you grown up?"
- Conversation needs to open your mind, to think
- Challenge to use socially-inspired topics and infuse with education

## 4. Groups were most effectively activated through

- Facilitator(s) setting positive dynamic
- Individual participation
- Finding common ground/interests
- Adopting a method to start fruitful conversations and questions in an attractive way
- Using what teenagers like, plus add information



# Next Steps\_

The interdisciplinary workshop held in August 2018 brought up a number of interesting findings, but also a number of pressing questions for each of the voices.

The workshop participants were asked to indicate what they would do next - what issues or questions would they explore and which methods would they use to do so?

1. Literature might focus on the bigger thing that comes from the conversation, as Tolstoy said an effective conversation is “When you are able to express what you think and understand what another things, and you can take this somewhere else.” We should look both at what is present and what is absent.
2. Medical Science might look at the hard end points, and map these back onto the text data to prove effectiveness.
3. Social Scientists might map the virtual care environment to understand how the space works.

4. Technologists might look at the quality of the conversation, and think about how best to organise the groups such that urgent and reflective conversations can happen in parallel. Mathematicians want to sink their teeth into the data, conducting a naïve analysis.
5. Implementation Scientists might look at how a methodology can be built that improves predictability of conversations, improves facilitation and improves efficacy of conversation with respect to particular behavioural outcomes. This is how we would get to scale.
6. Participants want to build the mentor program, because people who are living with HIV are better at giving advice. They want to focus on scaling up the program to their peers, particularly in disadvantaged areas.

The core team hope to secure funding to pursue in-depth analysis of the data corpus from each of the ‘six voices’. This would involve identifying specific methodologies within each voice, and allowing experts to apply

them to the data. Critically, this would involve a Participatory Action Research Cycle whereby the Khuluma mentors will be asked to reflect on, validate and add to insights generated by other five voices.

	Objectives	Methods
Social Science	To identify socio-cultural patterns both within and outside the text message corpus	Ethnographic analysis Qualitative field research
Technology	To explore the underlying structure and patterns of the text message data corpus and hypothesize the meanings behind them	Natural language processing Pattern analysis
Participatory	To identify relevant geospatial, cultural, language and behavioural patterns relevant to the analysis of other voices	Participatory mapping Thematic analysis of text message data
Implementation	To explore the impact of Khuluma support groups on the clinical and behavioural outcomes for participants	Retrospective clinical audit Interrupted time series analysis
Medical Science	To identify heard and soft markers of group efficacy from outside the text data in order to anchor the analysis	Literature review and meta-synthesis
Literature	To conduct a close reading of selected text message conversations in order to identify linguistic and social patterns in support delivery	Discourse analysis Linguistic analysis Thematic analysis
Layering insights through exploring scale, temporality, directionality and intensity		

Indeed, the ultimate aim of the 160 Characters Project is to develop an interdisciplinary methodology for evaluating the effectiveness of online communities and digital support groups globally. In the long term, it will involve adapting and implementing the methodology to

other existing online communities in partnership with governments, NGOs and national health services that use different platforms such as Facebook, forums, chat rooms, Whatsapp, or other bespoke mobile applications to meet the mental health and wellbeing needs of vulnerable populations.



# References\_

1. World Health Organization. Adolescent health epidemiology. [Online] World Health Organization; Available from: [http://www.who.int/maternal\\_child\\_adolescent/epidemiology/adolescence/en/](http://www.who.int/maternal_child_adolescent/epidemiology/adolescence/en/)
2. Vanable, P.A., Carey, M.P., Blair, D.C. et al. Impact of HIV-Related Stigma on Health Behaviors and Psychological Adjustment Among HIV-Positive Men and Women. *AIDS Behav* (2006) 10: 473.
3. Bekker L-G, Hosek S. HIV and adolescents: focus on young key populations. *Journal of the International AIDS Society*. [Online] Wiley-Blackwell; 2015;18(2[Suppl 1]). Available from: doi:10.7448/IAS.18.2.20076 [Accessed: 15th May 2018]
4. SHM Foundation. Khuluma: Addressing the mental health and wellbeing needs of HIV positive adolescents in South Africa. A findings report on the impact of Khuluma by the SHM Foundation. 2016. London.
5. Celum CL, Delany-Moretlwe S, McConnell M, et al. Rethinking HIV prevention to prepare for oral PrEP implementation for young African women. *J Int AIDS Soc*. 2015;18(4 [Suppl 3]). doi:10.7448/IAS.18.4.20227.
6. UNAIDS. The Gap Report. Geneva: UNAIDS; 2014.
7. Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011;365(6):493-505. doi:10.1056/NEJMoa1105243.
8. Hayes R, Floyd S, Schaap A, Shanaube K, Bock P, Sabapathy K, et al. A universal testing and treatment intervention to improve HIV control: One-year results from intervention communities in Zambia in the HPTN 071 (PopART) cluster-randomised trial. *Low N (ed.) PLOS Medicine*. [Online] Public Library of Science; 2017;14(5): e1002292.
9. Gray, Vawda, & Jack. *South African Health Review 2012/13*. Health Systems Trust. Durban, 2013.
10. UNAIDS. *Global AIDS Update*; 2016.
11. WHO. *Epidemic Update and Health Sector Progress towards Universal Access*. Progress Report. 2011. Geneva, Switzerland; 2011.
12. Kessler RC, Amminger GP, Aguilar-Gaxiola S, Alonso J, Lee S, Ustün TB. Age of onset of mental disorders: a review of recent literature. *Curr Opin Psychiatry* 2007 Jul;20(4):359-364
13. Kim S-H, Gerver SM, Fidler S, Ward H. Adherence to antiretroviral therapy in adolescents living with HIV. *AIDS*. [Online] 2014;28(13): 1945-1956. Available from: doi:10.1097/QAD.0000000000000316 [Accessed: 15th May 2018]
14. Pienaar & Visser. An exploration of the experiences of adolescents living with HIV. An exploration of the experiences of adolescents living with HIV, Vulnerable Children and Youth Studies. 2012; 7:1.
15. Gonzalez, J. S., Batchelder, A. W., Psaros, C., & Safren, S. A. (2011). Depression and HIV/AIDS Treatment Nonadherence: A Review and Meta-analysis. *Journal of Acquired Immune Deficiency Syndromes* (1999), 58(2).
16. Lowenthal E, Bakeera-Kitaka C, Marukutira T, Chapman J, Goldrath K, Ferrand R. Perinatally acquired HIV infection in adolescents from sub-Saharan Africa: a review of emerging challenges. *Lancet Infectious Diseases*. 2014;14(7): 627-639
17. National Department of Health. National Consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and management of HIV in children, adolescents and adults. South Africa: 2014.
18. Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., ... Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa. A qualitative investigation. *AIDS Care*, 22(8), 970-978. doi:10.1080/09540121003623693
19. World Health Organization, 2010. mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings. Geneva, Switzerland.
20. Nakimuli-Mpungu, E, Wamala, K, Okello, J et al. 2015 Group support psychotherapy for depression treatment in people with HIV/AIDS in northern Uganda: a single-centre randomised controlled trial. *Lancet HIV May*;2(5):e190
21. Patel V, et al. Treatment and prevention of mental disorders in low-income and middle-income countries. *Lancet*. 2007; 370: 991-1005
22. Dageid, W. Support groups for HIV-positive people in South Africa: Who joins, who does not, and why? *African Journal of AIDS Research*. 2014; 13(1): 1-11
23. Griffiths, K, Mackinnon, A, Crisp, D et al 2012, 'The Effectiveness of an Online Support Group for Members of the Community with Depression: A Randomised Controlled Trial', *PLOS ONE* (Public Library of Science), vol. 7, no. 12
24. Ali, K. Online peer-to-peer support for young people with mental health problems: a systematic review. *JIMR Mental Health*. 2015; 2(2):e19
25. Prescott J, Hanley T, Ujhelyi K. Peer communication in online mental health forums for young people: directional and nondirectional support. *JIMR Mental Health*. 2017; 4(3).
26. Clark HH, Brennan SE 1991 "Grounding in communication. In: Resnick LB, Levine JM, Teasley SD, editors. *Perspectives on socially shared cognition*" Washington DC: APA Books. pp 127-149.
27. Schober MF et al. 2015 "Precision and Disclosure in Text and Voice Interviews on Smartphones." *PLoS ONE* 10(6): e0128337.
28. Carron-Arthur, B, Reynolds, J, Bennett, K et al 2016, 'What's all the talk about? Topic modelling in a mental health Internet support group', *BMC Psychiatry*, vol. 16, no. 367, pp. 1-12.
29. Algtewi, E., Owens, J., & Baker, S. (2015). Analysing people with head and neck cancers' use of online support groups. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 9(4),
30. Love, Brad, et al. "Exploring Psychosocial Support Online: A Content Analysis of Messages in an Adolescent and Young Adult Cancer Community." *Cyberpsychology, Behavior, and Social Networking*, vol. 15, no. 10, 2012, pp. 555-559., doi:10.1089/cyber.2012.0138.