160 Characters_

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Adolescents Lives Workshop

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Background to 160 Characters Project

Overview of Project Khuluma

What is 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.

Khuluma is **peer led**, and where the participants can give and receive advice in a **safe, anonymous and moderated** space.

Accessible

Immediate

Tailored

How does Khuluma work?

1. Adolescents are recruited at different clinics

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

3. The support groups run for three months

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

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

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

Who are the adolescents that we are working with?

- Adolescents living with HIV in South Africa (ALWHIV). Over 15% of young women and 5% of young men aged 15-24 in South Africa are infected with HIV (UNAIDS).

- ALWHIV in LMICs, individuals 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.

- ALWHIV are at the increased risk of mental health problems which can in turn lead to poor mental health outcomes such as poor medical adherence

Understanding the needs of ALWHIV

- There is an urgent need to:
  - understand the barriers to accessing HIV services and adhering to medication
  - understand the mental health and wellbeing needs of ALWHIV
  - develop approaches to provide ongoing support that is immediate and accessible to all ALWHIV
  - innovate interdisciplinary, participatory methods for evaluating these complex interventions where adolescents are at the centre of the research cycle

Khuluma Data is unqiue

Khuluma's corpus of text messages provide a **unique insight** into the mental health needs faced by ALWHIV with over 60,000 text messages between 160 participants

Khuluma and can help us to **design appropriate interventions**

Aim of the 160 Characters Project

- 160 Characters aims *to develop an interdisciplinary arts, health and humanities methodology for understanding the attitudes of adolescents towards their own health; and subsequently, to develop strategies, techniques and solutions to serve their needs.*

- The project is a collaboration between the SHM Foundation, UCL's Institute of Global Health with support from the Desmond Tutu HIV Foundation, STEMA, Superbeing Labs and Rocket.Chat. However, at the core of the project have been the Khuluma adolescent peer mentors – Desmond, Andani and Given.

160 Characters Methodology

- The project began at a workshop in 2017 that addressed the question: *can we create a different way of looking at the Khuluma text messages?*

- The outcome of this workshop was the realization 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 the technology to develop a participatory, interdisciplinary methodology

6
VOICES

Six Approaches

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

Co-designing 160 Characters methodology with the Khuluma mentors

Pretoria workshop

- The *Adolescent Lives Grand Challenges* award facilitated two cross-disciplinary workshops, one in London with 18 participants from the 'six voices' and a workshop in Pretoria with the Khuluma mentors.

- The purpose of the two day workshop was 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 workshop included 10 mentors and involved a range of activities, a craft workshop, presentations and an in-depth analysis of the text message data.

Effective conversations: adolescents' perspectives

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

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

- Topics that work:
  - 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
- Group activation through
  - Facilitator(s) setting positive dynamic
  - Individual participation
  - Finding common ground/interests
  - Adopt a method to start fruitful conversations and questions in an attractive way
 - Use what teenagers like, plus add information

Thematic Analysis

- Analysis showed that there are five thematic concerns that arose when workshop participants analysed the data. These include self identity, relationships and responsibility, community and acknowledgment, society and influences and HIV.

- Insights from each of these thematic areas were summarized and visually presented in tables.

An example of the thematic analysis: Self & Identity

Literature	Medical Science	Implementation	Participatory	Technology	Social Science
There is a lot of maschismo, tough guy speak, in contrast to the weakness of their disease	What does 'well' mean for these adolescents, physically and emotionally?	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.	We are in a relationship to ourselves and must communicate to ourselves	Its great they're talking about hopes and dreams, but sometimes it feels utopian, giving them false hope	Individuals can pose their problems to the group to collectively problem solve
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	The text messages are an unsolicited source of data on what they think is important	Its like being a 'mystery shopper' reading this data, providing the kinds of insights we can't get elsewhere	Honesty and self acceptance mean increased confidence to be ourselves, and to reveal our HIV status.	Sometimes I think it would be useful if they had a change to be more slow and thoughtful in their responses	Its like in the groups they have an alternate subjectivity or sense of self

Policy Implications

- Provide insights into the mental health and wellbeing needs of HIV Positive Adolescents that can be used to improve and tailor adolescents services.

- Provide new insights into the barriers to HIV service access and adherence that be used to tailor services

- A new participatory, interdisciplinary method for addressing complex problems in global health.

- An evidence-based version of the Khuluma model tailored through new participatory insights generated by HIV Positive Adolescents

- A global network of scholars working on online communities to support adolescents in LMICs
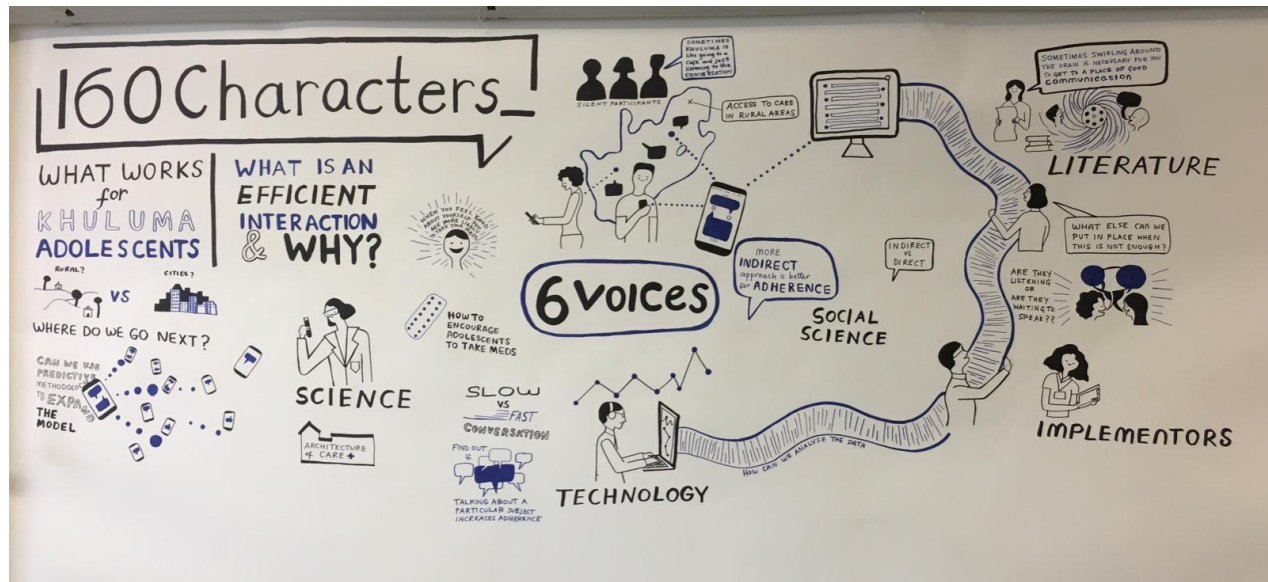
8. Next Steps

Dissemination
Grants
Papers
Technology
Other