John Snow LABS

DATA PHILANTHROPY: A CASE STUDY

CLIENT: SHM FOUNDATION

PROJECT: APPLYING ADVANCED ANALYTICS TO HELP IMPROVE MENTAL HEALTH AMONG HIV POSITIVE ADOLESCENTS IN SOUTH AFRICA

"John Snow Labs are professional, enthusiastic, and knowledgeable, and it has bee an absolute pleasure working with them. I recommend them highly. "

Anna Kydd, SHM Foundation Director

"John Snow Labs' analysis enriched and enhanced our Khuluma findings, which were presented and well-received at AIDS 2016."

Zuzana Figerova, SHM Head of Development

"John Snow Labs' analysis has given me new ideas for exploring future data we may collect, as well as helped to inform the kinds of data we need to complete further analysis in the future."

Jennifer Koen, Khuluma Project Manager

"It was a pleasure to work with John Snow Labs and we were deeply impressed by their passion for the work we do and by their drive for extracting the best data from Khuluma."

Anna Kydd, SHM Foundation Director

There is an increased risk of mental disorders in adolescents with HIV/ AIDS in South Africa and the situation can be worsened by depression and anxiety. The Khuluma project was carried out to enhance positive mental health amongst adolescents in South Africa with the aim of reducing and ultimately preventing the spread of HIV/ AIDS. Khuluma, which is an integrated, cost-effective and scalable health platform, leveraged the power of small mentoring groups in facilitating interactive closed groups that comprise of 10 to 15 participants.
John Snow Labs helped with the analysis of data obtained during this project as a turnkey philanthropy project.
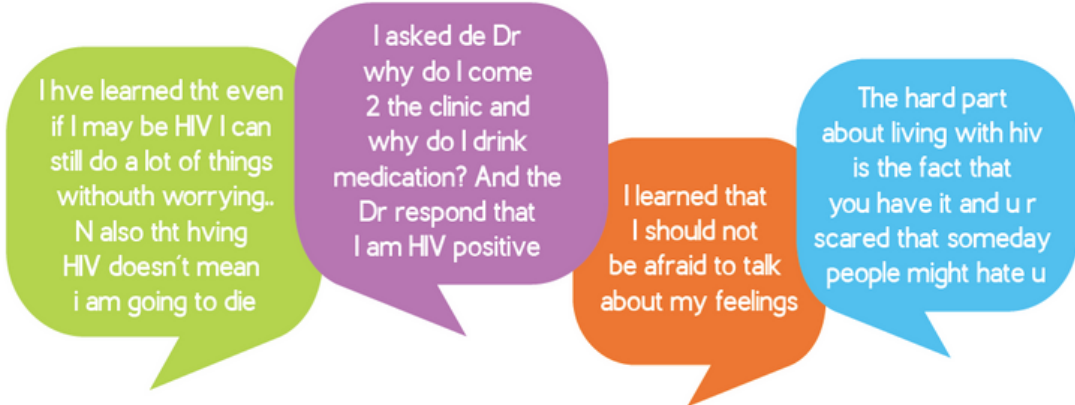
↑**6.8%**
FEELINGS OF
SOCIAL SUPPORT

↓**25.8%**
INTERNALISED
STIGMA

↑**17.4%**
REGULARLY TAKE
THEIR MEDICATION

S M T W T F S

WHAT IS KHULUMA?

No one had ever asked me to talk about my feelings in this way before. As I opened up more I learned to trust and could share more

I feel more comfortable talking to people in this group because we all have HIV- I am not the only one

I learned that I should not be afraid to talk abut m feelings.

I learned that people living with HIV can do what people not living with HIV can do.

A mobile phone support group intervention for HIV positive adolescents in South Africa to address their mental health and wellbeing needs.
Owing to a conglomeration of psychosocial risk factors, including the lack of social support, adolescents living with HIV/AIDS (ALWHA) are at increased risk of mental health problems, leading to poor health outcomes. With this challenge in mind the SHM Foundation designed and implemented the Khuluma project that aims to address the mental health and well-being needs of ALWHA.
Khuluma uses widely-available and inexpensive technology (text messages), to overcome some of the obstacles which might prevent individuals from accessing support.

I hve learned tht even if I may be HIV I can still do a lot of things withouth worrying.. N also tht hving HIV doesn't mean i am going to die
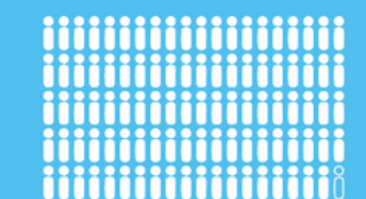
I asked de Dr why do I come 2 the clinic and why do I drink medication? And the Dr respond that I am HIV positive

I learned that I should not be afraid to talk about my feelings

The hard part about living with hiv is the fact that you have it and u r scared that someday people might hate u

METHOD · · ·

Participants are asked to complete a check-list about treatment adherence before enrolment and after taking part in Khuluma. Over three months, participants can freely communicate with one another along with a facilitator. The Khuluma project team extracted text-message conversations, from over 40,000 messages, related to treatment, medication, and adherence, amongst 99 participants.

3 MONTHS

AUG JUL JUN

40,000 SMSs

99 PARTICIPANTS

KEYWORDS

TREATMENT
MEDICATION
ADHERENCE

· · · RESULTS

Although participants reported at enrolment that medical adherence was not a major issue for them, during their time in Khuluma they admitted that they missed taking their medication for a range of practical and emotional reasons, including disrupted routine, a lack of social support, feelings of anger, fear of stigma and trouble managing side-effects. Participants encouraged one another to take their medication and discussed the underlying reasons, such as stigma, that had a negative impact on their medical adherence. Overall, there has been a 17.4% self-reported increase in adherence levels amongst in the number of participants who self reported that they take their antiretroviral medication.

S M T W T F S

S M T W T F S

CHALLENGES

Prior to the Khuluma project, participants had insufficient access to social support, which contributed to increased depression. Participants also had a low level of basic understanding of HIV and its transmission as well as infections such as pneumococcal disease or TB.

At least two-third of the participants indicated that apart from their healthcare providers and immediate care-givers, they had not disclosed their HIV status. This stigma is responsible for anxiety and depression and inhibits disclosure.

Moreover, poor adherence was prevalent among the participants prior the Khuluma project. This was responsible for increase in viral resistance and severe opportunistic infections.

Support groups comprising at most 15 people were set up. The support groups ran for 3 months every day after school hours. Topics were brought up by the facilitators and these topics were discussed within the groups. Guest speakers were also invited to coordinate facilitated discussions on topics like nutrition, education, career and sexual health. The data analysis challenges in understanding the impact of the project on participants include:

• Over 40,000 unique text messages were exchanged in the support groups during the project.
• This required some natural language processing, with capability to understand the noisy, slang-filled language of text messages.
• Multiple other datasets were available including quantitative data collected through the baseline and exit questionnaires.
• Limited labeled data was available to classify and categorize messages.
• The data had to be anonymized prior to analysis.

OUR APPROACH

The data science and analytics challenged presented by this project included the fusion of multiple 'noisy' data sources, analysis of free-text messages, and the large scale of the overall dataset. The John Snow Labs team used elements of:

• Natural language processing
• Time series analysis
• Classification
• Clustering
• Advanced statistics

In addition to multiple data cleansing and normalization techniques. These had to be run at scale multiple times, to iteratively apply feedback from the SHM Foundation project team on what was important and useful.
These insights not only show the full impact of Project Khuluma on its participants, but also contribute to the global knowledge base about addressing the AIDS epidemic among adolescents.

HOW WE HELPED

The results from John Snow Labs' analysis that were most helpful to the presentations for AIDS 2016 were:

- **The findings showing the proportion of participants who felt that Khuluma helped in making a positive difference in how they felt about their status**

- **The findings about the increase in the number of participants who reported being able to discuss their problems with friends and family**

- **The findings showing a decrease in feelings among participants that they would be discriminated against by others, because of their status**

- **The findings showing the number of messages shared in the groups about adherence and encouraging one another to take ARVs, and how the conversations about ARVs became more frequent later in the groups**

Our involvement in Khuluma's data analysis helped in breaking down the barrier inhibiting the success of the support groups' activities. These barriers include:

• Stigma and Discrimination
Many fear that disclosing their HIV status can make them experience stigma and discrimination in their communities. Khuluma allow these adolescents to communicate freely about how they feel about their communities. John Snow Labs used aggregate data to support that Khuluma provides them better understanding about their communities by supplying a lower stress environment which helped reducing their overall sense of stigma and discrimination by 10%.

• Access To Support Group
This is a crucial barrier that was tackled since HIV positive adolescents often have complex and busy schedules that may hinder them from attending a support group. Using text message let these adolescents communicate at any place any time without physical appearance. John Snow Labs analyzed from these text messages that there is a 33% improvement in feeling towards social support.

• Social Isolation
Khuluma identified the need of setting up support groups tailored to adolescents since it will be challenging to discuss age-specific topics when covering a wide age range. John Snow Labs was able to analyze age-specific topics and arrange most frequently occured key terms in word clouds that were deemed critical in participating teenagers' feelings that they wouldn't share otherwise.

Having support from a team of data scientists and experts provided SHM Foundation with a different and valuable perspective on the data obtained and it energized SHM Foundation to carefully consider the kinds of data collected in the future and also provided them with avenues for further exploration.

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DETAILED RESULTS

• Social Support

Analysis of the pre- and post-Khuluma questionnaires revealed a significant increase in feelings of social support amongst participants. On a scale 12 of 0 to 60, where 60 indicates a high level of perceived social support, scores increased by 4.4 points which is synonymous to 33% increase. Most of the 44,000 messages sent demonstrated a huge need for adolescents to have social support.

• Knowledge of Their Illness

Participants were able to receive accurate information about HIV and were also able to correct the misunderstanding they have had.

• Reduction of Internalized Social Stigma

Analysis of the pre- and post-Khuluma questionnaires revealed a reduction in internalized stigma. On a scale 14, from 0 to 7, with 0 indicating very low and 7 indicating very high levels of internalized stigma, scores fell by 1 point. This is synonymous to 10% decrease.

• Treatment Adherence

Throughout Khuluma, participants opened up and also admitted that they missed some of their medications due to various reasons. Participants encouraged each other to take their medications through direct messages like "Hi guys, did u take ur pills?" and "You must take it every day."

CONCLUSION

Peer support in mental health that is built on shared personal experience and empathy leads to enhanced self-esteem and social functioning.

Support, be that social, emotional or practical that is mutually offered and reciprocal enables participants to benefit from the support whether they are giving or receiving.

> **About partnering with John Snow Labs on future projects,**
> **Anna Kydd has this to say:**
> "John Snow Labs provided professional and friendly service to us as well as thorough analysis of complex data. Where relevant, I think they could contribute positively to future projects. I would recommend them for their availability, personal service and committment and enthusiasm for the projects they assist."