

HEADS-UP: PROJECT SUMMARY FOR CLINICIANS, SUPPORT ORGANISATIONS AND FUNDERS



HEADS-UP

HIV EMPOWERING ADULTS' DECISIONS TO SHARE - UK / UGANDA PROJECT

OBULWADDE BWA MUKENENYA BUWA ABANTU ABAKULU AMAANYI OKUSALAWO OKWOGERA KU MBEERA ZAABWE

HIV SHARING

There are over 2 million young people living with HIV globally and many find telling others about their HIV (also known as sharing their HIV status or onward HIV disclosure) difficult.

HEADS-UP

We developed HEADS-UP (HIV Empowering Adults' Decisions to Share – UK/Uganda Project) to help support young people with perinatally acquired HIV (18-25 years in Uganda, 18-29 in the UK) to make decisions about *whether* and *how* to share their status.

Participants in the UK were recruited from clinics in London, Birmingham, Manchester and from a nationwide UK charity. In Uganda, they were recruited from the Kampala region.

Young people were randomly allocated to one of two conditions:

1. THE INTERVENTION CONDITION

Participants in this condition met with two therapists (one living with HIV, the other a health professional) in a group format for three sessions. They also had an individual session with one of the therapists. During the sessions young people took part in exercises about sharing their status with other people, including discussing videos about sharing. The intervention was delivered in person in Uganda and remotely in the UK.

2. THE STANDARD OF CARE (SOC) CONDITION

Participants in this condition did not take part in the programme but attended their usual clinic appointments.



Assessments were carried out at: Pre-intervention /baseline; Post-intervention (intervention group only); and Six-month follow-up. In addition, we interviewed intervention participants at the post-intervention and six-month data points, SOC participants at six months, and therapists at the end of the study.

WHO TOOK PART IN THE STUDY?

142 young people were recruited to the study:

94 in Uganda



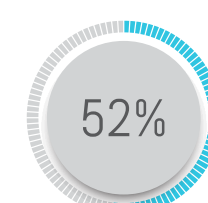
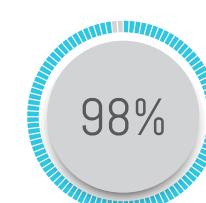
48 in UK

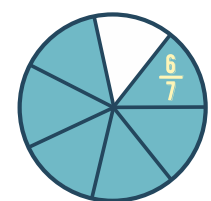


Most people at the start of the study had never shared their HIV status with anyone or had only told very few people.

WAS THE INTERVENTION ACCEPTABLE AND FEASIBLE?

At six-month follow-up, 92/94 (98%) participants were retained in Uganda, 25/48 (52%) in the UK.





The intervention sessions were rated as highly acceptable (UK mean: 6.6/7; Uganda mean: 6.8/7). The overall rating of the intervention sessions was very positive in both countries (UK mean 6.47/7; Uganda mean: 6.53/7).

QUANTITATIVE FINDINGS

Only 1 in 4 of those in the standard of care condition said that they had spoken to a health professional about HIV sharing in the previous 6 months. This suggests that there is a need to provide more HIV sharing support.

When we compared those in the intervention and in the standard of care condition, there was good evidence that the intervention improved wellbeing. There was also some evidence that the intervention resulted in young people being more motivated to share and intending to share their status in the next 6 months.



Young people benefited from meeting other young people living with HIV:

"I did meet people and I was able to, at the end of the whole study, stay in contact with them and also I was able to actually open up and connect with the other people at the same time and share similarities and differences" (UK participant)

"Oh, I don't know it just felt like an instant family, like we just connected we all have different, such different personalities and characters but just came together, it was just amazing, it was really, yes" (UK participant)

They were able to reflect on what they had learned about HIV sharing:

"I learnt that you can choose to open up to one person and then you can also choose to open up to a group. I learnt how people can react differently. Like how it helps you feel as a person because it was like when you open up, it is easier for you to take medicine and not hiding in the corners. Yeah, I learnt that opening up has its advantages." (Uganda participant)

Some young people spoke about the impact of the intervention on their HIV sharing decisions:

"I would say it empowered me to move my timeline forward. For me personally it made me realise that sometimes I-over preparation is a thing... it was more like you can do this, you actually have it in you, stop messing around, like there's no there's no time like the present." (UK participant)

"I feel like it kind of pushed me and encouraged me to actually share with a few more people and I felt very, like, what's the saying? Like you know when a weight it lifted off your shoulder? I kind of felt like that yes" (UK participant)

CONCLUSIONS AND FUTURE WORK

The promising findings of HEADS-UP suggest that there is a need for structured HIV sharing support for young people living with HIV. Now, we plan to develop guidance and resources for young people living with HIV, and professionals who work with them, around HIV sharing. We are also developing and testing a digital version of the HEADS-UP intervention for adults in the UK living with HIV of sub-Saharan African origin. Ongoing work should be funded given the importance of HIV sharing for people living with HIV.