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We would like to thank the children who took part in Young Lives, their carers and health care workers. We are grateful to the Department for International Development (UK Government) for funding and our organisations: Joint Clinical Research Centre, Medical Research Council/Uganda Virus Research Institute, Baylor Uganda, the London School of Hygiene and Tropical Medicine and the MRC Clinical Trials Unit at UCL.

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UK aid from the British people

This is the story of a young Ugandan girl living with HIV. Kristina is not a real person. Her story is based on the stories of the lives of the young people living with HIV who took part in the ARROW Young Lives research project in Uganda and Zimbabwe.

The aim of the ARROW Young Lives project was to find out how young people between the ages of 11 and 13 years managed being HIV-positive. We interviewed 104 young people, their carers and health workers. Some of the young people were interviewed four times, over 18 months.

We hope this story will help people to understand better what it is like being a young person living with HIV.

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The bright sun has chased away the rainy season. It is a beautiful day.

I am Kristina. I would like to share with you the story of my life. I am 15 years old and I am also positive. I live with my grandmother, my older sister Clara, and my younger sister Nosa. I am 15 years old and I have some way to Insecurity... Sometimes, that is a burden, and it does not make me happy. But I am not positive.

When I was very little — about six years old — I used to fall sick all the time. I was bedridden in my house and often had fever. I did not know why. Sometimes, I could not go to school. Sometimes for a week, I had to take rest every day.

Seanor, I don't feel good. I don't think I can go to school today.
I have been taking these drugs for so long, grandma. I feel so new and I want to take them.

Kristina, come in. Grandma is going to help you with your charges.

Come on, Kristina. You have to take your charges now.

Every day I bring the child to the drugs on time. Every evening she goes home at 6.30, and as she enters the room, she always places a glass of water beside my bed. But when she enters the room, I am already sleeping.

Kristina, Kristina, come in now.

I have to wash the dishes. Every evening I have to wash the dishes, and I am so tired. Every evening I have to wash the dishes. Every evening I have to wash the dishes.

Mama, do you know how many hours I have to work? It's so long. I don't know how to do it.

Mama, do you know how many hours I have to work? It's so long. I don't know how to do it.
THEN I HAD A VERY LEAVESI. OR, AT LEAST I THOUGHT IT HAS VERY COLDER AT THAT TIME.

I HATE THESE DRESS! I WILL NOT TAKE THEM ANYWAY! I VOMIT! DRESS, I AM NOT LOOKING. I CAN JUST WEAR THEM, WITHOUT EVEN LOOKING AT IT, YOU DO NOT DRESS THE WOMEN DO. NOW, I DECIDE TO BURN THE SLAY...NO DAE.

SOON I STARTED TO FEEL BAD AGAIN, BUT I STILL DO NOT KNOW WHAT HAS REALLY HAPPENED WITH ME.

GRANDY, LOOK AT THIS WATER, IT'S ALL OVER MY BODY.

GRANDY: THE SOAP DOESN'T RINSE OFF. I CRIED AND THE BATH WAS DONE TO MY DAAL. LOOK AT THESE UGLY SONGS ON MY NECK AND CHEEK.

COME ON KRISTAL, WE HAVE TO GO TO THE GYM FIRST TO COLLECT THE RESULTS OF YOUR TEST. THEN WE HAVE TO SEE THE DOCTOR.

WHAT'S SONGS ON YOUR CHEEK? DON'T WANT TO TALK ABOUT WHY CAN'T I BE HERE WITH THEM?
I HAD TO CUT OUT FOR A WHILE. BOTH THE CHILDREN HAD RUN AWAY INTO THE DOCTOR'S OFFICE.

WE WENT INTO THE COUNSELLING ROOM. THAT'S WHEN GRANDPA CAME IN.

I WAS SICK, AS I HAVE A HOLE. I WAS CALLED BACK INTO THE COUNSELLING ROOM. AND THAT'S WHEN GRANDPA CHANGED HIS MIND.

THE NEWS HITS MY HEART. I FEEL SICK ALL OVER MY BODY AND TEARS SLOWLY TRICKLED DOWN MY CHEEKS. GRANDPA DIED TOO. HOSPITALS. THE NEWS HIT THE AIRPORT AND CALLED ME DOWN.

IF YOU REQEST TO DROP

NO, THE DRUGS WILL KEEP YOU SANE AND HEALTHY.
I was worried about what other people would think of me.

Well, Granny now treats me differently than other kids. I don’t get the secret handkerchief to clean my nose. She doesn’t tell me when I’m dirty because she thinks I’m too old. She doesn’t speak to me when she walks past me in the street or when I’m standing in the doorway. I don’t understand why they treat me like this.

Most of us children try to keep our eyes open to see what people are saying behind our back. We tell other people who don’t treat us very well.

After that day, Granny and I never talked about it again. I wonder why Granny never talks to me about what I learnt at the clinic that day.

Very often, there are too many kids in our class. We are forced to share our chairs. I tried to talk to some of the kids in our class about it, but they didn’t talk to me about it either. I think it’s because they don’t understand why they have to share their chairs.

I don’t have any questions about why we could talk and get answers to all those questions that trouble me.
Granny and I did not speak about my parents but one day, a couple of times and I was given Granny’s phone number to call her any time.

**I DO NOT GET AN ANSWER TO THE UNANSWERED QUESTION IN MY HEART.**

**WHO ARE THEY?**

**HOW DO I GET THEM?**

**BADDY: A YEAR AFTER YOUR MOTHER PASSED ON, YOUR AUNTIE RALPH, YOUR AUNTIE VELLEN AND I TOLD YOU ABOUT ME AND YOUR FATHER.**

**GRANNY: WILL I TAKE CARE OF YOU AND CLARA.**

But why did I get Niniro? And why did both my parents and Niniro pass away? I was always left with my questions, but it never occurred to me that I was very young and that I was not aware that there were very serious questions among children who had been orphaned or whose parents had passed away. I was not aware of the need for confusion and misunderstanding about these children.

Then one day, Granny answered one of my questions after I got some information about Niniro.
In Primary five another teacher talked about my prevention measures. I also always attended Presidential initiatives on AIDS awareness and education. One day, she even taught us about the dangers of AIDS.

What are the dangers of HIV/AIDS?

- Thinness
- AIDS
- Fatigue
- Has recurrent fever

Prevention is better than cure.

You must avoid getting HIV.

What is the point of all these diseases? I don’t want any. I just want to be healthy. If I am infected with HIV, I will not live for long. I will not support my family. I will not be able to support my family. I will not be able to go to school.

During the primary sessions in school, the teacher talked about my prevention. But no one talked about all these diseases. Even doctors like the one who I used to visit may not ask questions about prevention. But also on supporting us in our daily lives.

When I was little, I used to live in a neighborhood where everyone knew each other. When the teacher went to my house and told her, she said, “No, she is not a child. She is not alive. She is not healthy.”
I did not want anyone to know that I was left-handed. I was afraid that the children would stop playing with me once they knew about it and start referring to me as such.

Thank goodness our school uniform was a long-sleeved shirt with a short skirt. I hid my left hand behind my back, and I pretended not to see the kids playing.

I was a member of our class team for the short-relay.

Our class won. I was told to take part in the short-relay. The principal even said that I was the fastest.

Kristina, since you are the smallest person in the team and the fastest, I suggest you take the last position in the relay.

I was too excited to remember that I had sore arms and legs, so I wore my T-shirt and a pair of shorts. I took the first position on the field for the short-relay.

The blue uniform is very nice. It seemed like we were going to win, but alas! No sooner had the baton been passed to me than I tripped and fell down. Our team was never the same.
Our class was very disappointed. At lunch time that day some girls shared horrible things about me. I was heart-broken.

I went to the shop. I just ran home to Gran.

Gran, what’s the matter with me you crying?

Ooh, Gran, it was awful. They all know they were so kind to me. They hate me. Why? Why?

Now, now, child. Tell me what happened. Tell me everything.

Don’t worry, baby. The girls will know you are a good girl. They say you are not your faults are not big.

I don’t feel like playing, Gran.

Thank goodness class has gone away to secondary school now I won’t know about it.

If you ever do this again, I will knock you senseless. Now as a punishment you will keep the garden neat for a whole week.
Jr. Sav. Anon. / Mrs. Sav. Anon. (Note: The characters are not clearly visible in the image.)

Mrs. Sav. Anon. says, "I want to know why the government will not build a school for the people." Mrs. Sav. Anon. then turns to the next page:

..."You need to find another school."
The sun is now quite high in the sky; it is still cool.

I am fine, but now I am also happy to be here.

I must say my study area is

before I leave NYC, I should

like to share some

thoughts with you.

To other young people who, like me, are living with HIV,

"Let's take our drugs well so that we lead healthy lives and achieve our dreams.

To those who take care of us:

"Love us and encourage us to take drugs regularly, so that we don't fall sick like

we were before taking AIDS drugs.

To our healthcare workers:

"Please continue giving us drugs so

that together we can fight the loved

HIV/AIDS."