

We are all the same

The results of the AALPHI study

For young people living in England, what is the impact of living with HIV from a young age and taking medication?



What is AALPHI?

AALPHI stands for the Adolescents and Adults Living with Perinatal HIV cohort.

AALPHI was looking at what effect **growing up with HIV** might have on young people's development as well as their physical and mental health. The study included:

- Physical measurements looking at weight, height, heart, levels of HIV virus and strength of the immune system.
- Interviews and surveys about sex, drugs, alcohol, feelings and emotions, taking medicines and moving from paediatric care to adult care.
- Computer games to test cognitive abilities, memory and problem-solving.

We spoke with **318 HIV positive** young people and over **100 HIV negative** young people who were from similar backgrounds. Half of the HIV negative young people were brothers & sisters of the HIV positive young people.

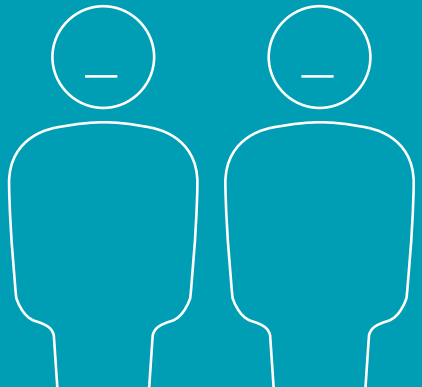
Depression and anxiety

Young people living with HIV are no more likely to get depressed, sad or anxious or to self-harm than HIV negative young people.

“Many young people can get depressed for regular reasons, such as issues at home or inside school but there can also be issues around HIV-related stigma and the struggle of accepting your status.”

In AALPHI, HIV positive and HIV negative young people were more likely to be depressed if: they were male, one or more of their parents had died, they had been excluded from school and they had lower self esteem.

It helps everyone to talk about feelings or worries and not think you have to manage them alone.



How your brain is doing

I was sick as a baby

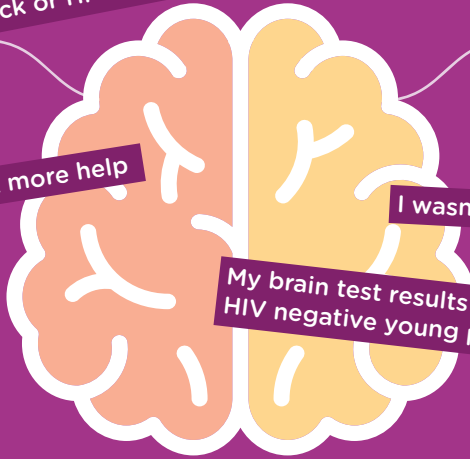
My brain test results were not as good as those who hadn't been very sick or HIV negative young people

I'm still fine

I might need a bit more help

I wasn't sick as a baby

My brain test results were similar to most HIV negative young people of my age



HIV positive and negative young people had similar results on AALPHI tasks measuring how their brain was working. Some HIV positive young people who had been very sick performed less well on some tests. But having HIV should not prevent anyone from achieving at school or in their future life.

Taking medicines (or not...?)



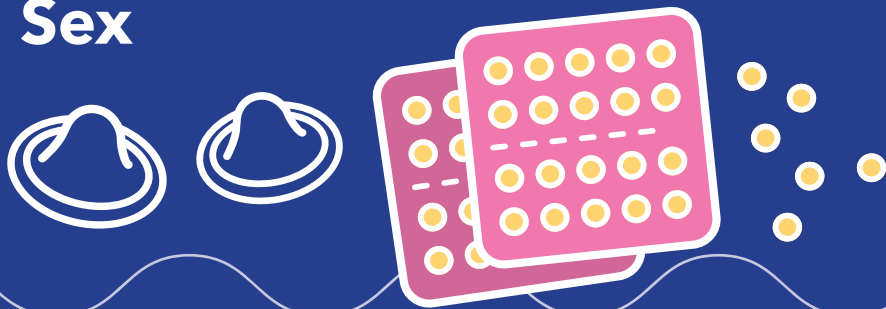
“Looking after yourself is important and taking medications is a form of looking after yourself in order to stay alive and keep healthy and by not doing that I was putting myself at risk”

“...taking medication should just be like brushing your teeth.”

About 40% of young people reported missing their HIV medicine especially at the weekends

Almost a third of the HIV positive young people had missed 2 days or more in the previous month

Sex



- HIV positive young people were having a similar amount of sex to the HIV negative young people and to the general population of young people.
- The majority of the HIV positive group were having safer sex, but there was still a small number with viral loads that were more than 50 (detectable) having unprotected sex.



What about when I move to adult care?

Most people were as happy with their adult clinic as their paediatric clinic.

Adult care was as flexible and their staff were as friendly.

“I didn’t have to go there with my mum all the time so I took more responsibility for myself”

“My adult clinic was a sexual health clinic which was daunting for a young 14 year old”

“I prefer it to paediatrics but the whole transitioning was not fun”

There were a few things that the HIV positive group could improve on in terms of their HIV knowledge. Some were unclear about the names of their medicines, or their last CD4 or viral load values, and were unsure of the side effects of their HIV medicines.



Find out more

For further info and support relating to children with HIV in the UK and Ireland, visit:

CHIPS

www.chipscohort.ac.uk

CHIVA

www.chiva.org.uk

