

### **EDCTP abstract (300 words)**

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**Title: 'Nothing about us without us': Multi-country adolescent patient-led recruitment information in the Long-Acting Treatment in Adolescents(LATA) randomised trial – an animated video to compliment 'traditional' participant information**

#### **Background:**

Participant information sheets and consent forms (PIS&C) in paediatric/adolescent clinical research are predominantly produced by adults. They are long and complex, meeting ethics, regulatory, and where applicable, pharmaceutical industry requirements, rather than the target audience. Young people report they do not understand much of the information provided, so do not read it, and rely on conversations with trusted Healthcare Providers. LATA(NCT05154747) being conducted by the BREATHER Plus Consortium, is the largest randomised trial of long-acting injectable antiretroviral therapy in virologically suppressed adolescents aged 12-19 years living with HIV-1(ALWH). LATA has 'Youth Trials Boards (YTB)' in the participant countries (Kenya/South Africa/Uganda/Zimbabwe) that consist of supported, structured groups of ALWH who are active partners in the development and delivery of LATA, which started enrolment in May 2023.

#### **Methods**

YTB members attended a global digital meeting to explore what information their peers need to give proper informed consent/assent and what medium would best deliver this.

#### **Results**

The group agreed a short, engaging video would provide core information on how the medicine works, the injection experience and trial requirements. Youth engagement specialists worked with animators to develop a concept and provisional script. The process included ongoing 'science and youth' checks. YTB members lent their voices to ensure the

video was in local languages. The final video was 5-6 minutes long (u-tube link to follow). All the national ethics committees have approved the video.

### **Conclusions**

The LATA video compliments the traditional PIS&C and was made through genuine youth engagement. The process allowed the young people to decide the format and content, whilst ensuring it correctly represented the trial. While this video is an adjunct to the PIC&S, in future, videos such as this could replace much of the lengthy complex language provided to trial participants, this merits further discussion with ethics committees and regulators.