

Findings from global consultations with adolescents living with HIV on the acceptability and accessibility of long-acting injectable ART.

#71

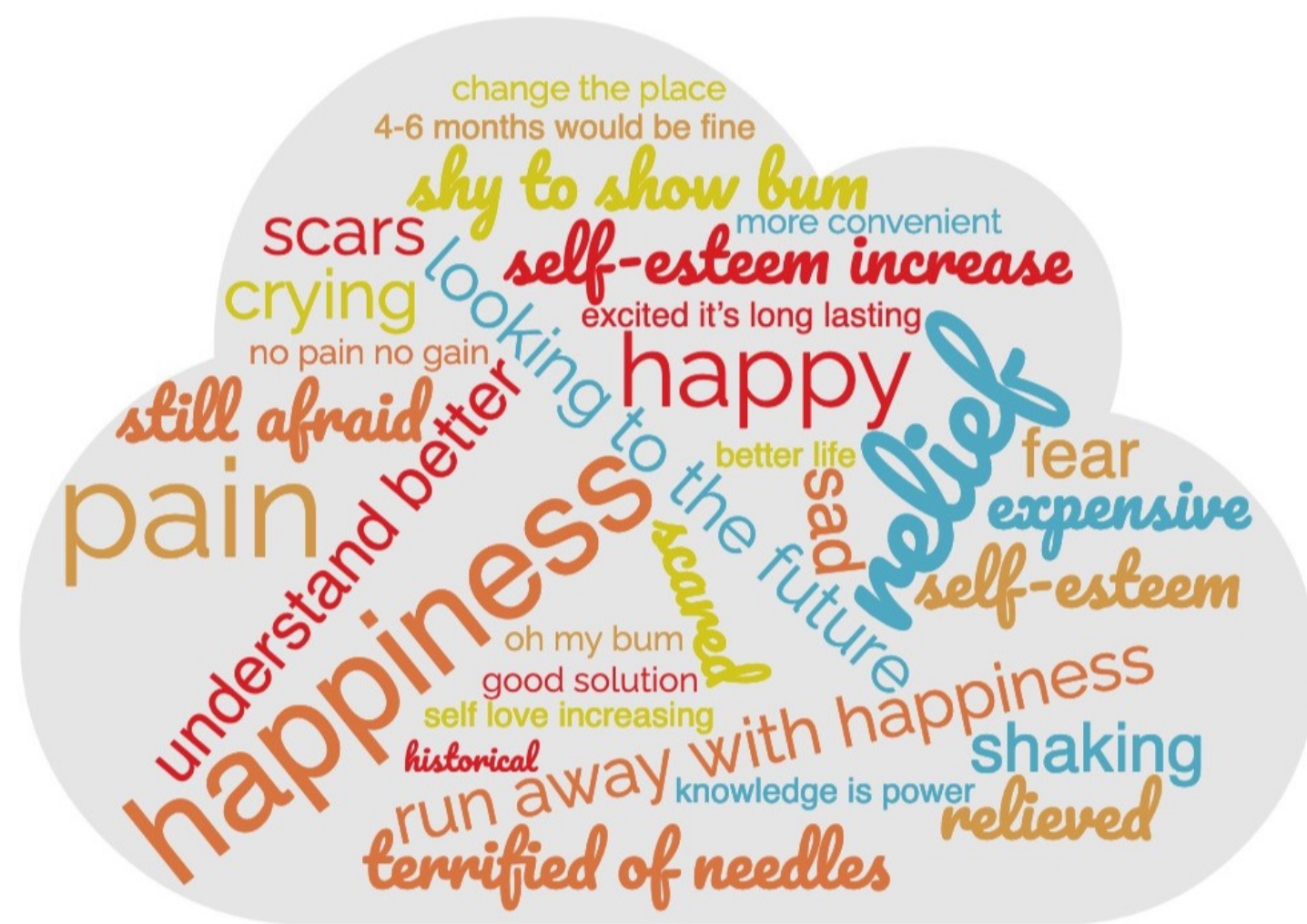
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Background

The advent of injectable long-acting anti-retroviral therapy (ART), has been seen by many as a solution to poor adherence in young people living with HIV. But to-date, no-one has actively sort to open a dialogue with this group to explore their thoughts and feelings towards this medication, how acceptable they feel it is to them and their peers and how accessible it would be.

Since 2017, **Fondazione Penta ETS** has developed models of youth participation in clinical trials and discussion around research. With support from ViiV Healthcare, Penta developed and delivered a project called 'The Long-acting Injectables Advisory Group'. Its aim was to specifically engage adolescents (13-19 years of age) living with HIV across four continents, providing them with the space to explore and learn about long-acting injectables, and then discuss possible barriers they and their peers may face and solutions for healthcare providers.

Image: After learning about long-acting injectable ART, the young people were asked to share the first word or words that came into their heads.



Source: Long-acting injectables workshops

The project recruited local NGO Partners from Sub-Saharan Africa, Latin America, Southeast Asia and Europe through an open tender process. All needed to currently be supporting young people living with HIV. The project partners were:

- **Foundation for Studies and Research on Women (FEIM)**, EnREDando Project, Argentina.
- **Hillcrest AIDS Centre Trust (HACT)**, South Africa
- **SEARCH Research Foundation (SRF)**, Thailand
- **Mildmay Uganda**, Uganda
- **Chiva**, United Kingdom

Materials & Methods

Each partner was asked to recruit a minimum of 8 adolescents living with HIV and provide transport, a safe place to meet and refreshments for participants to attend a half-day workshop. Budget was also provided for a small payment to participants to acknowledge the time they were giving.

The content of the workshop was carefully structured to provide the attendees with knowledge about long-acting injectable ART, but also activities to consider their experiences of adherence and HIV stigma. From this point, they then could explore issues and barriers they and their peers may face in accessing long-acting injectable ART. All materials were youth-friendly, with games, videos, activities and group work. The content was strictly neutral to allow the young people to explore their own thoughts and feelings and consider what is right for them.

Image: Picture drawn by a young person from Thailand.



The workshops were delivered in-person between April – May 2023. All workshops (with the exception of Thailand) were run by an independent consultant. Discussions were recorded, transcribed and then the findings were collated and a thematic review was undertaken.

In June 2023, two representatives from each group were invited to join a digital Advisory Group meeting to speak with ViiV Healthcare staff and share the thematic findings, as well as country specific discussions, from the workshops. Prior to this meeting, a digital planning meetings was held where the young people could practice using Zoom and practice presentations. Thai, Spanish and Isizulu simultaneous interpreters were used to support communication and to not limit participation to those who were fluent in English.

Summary of the work-shop content

The workshop used interactive youth-friendly activities, videos and small discussion groups. The areas covered were:

- Adherence and taking medicine, with a focus on the impacts of internal and external HIV stigma on young people's lives.
- How long-acting injectable ART works, how it is administered and what this might mean for young people.
- Cultural attitudes to medication through pills and injections.
- Exploring the potential barriers young people may face if offered long-acting ART, and ways which these barriers may be overcome.

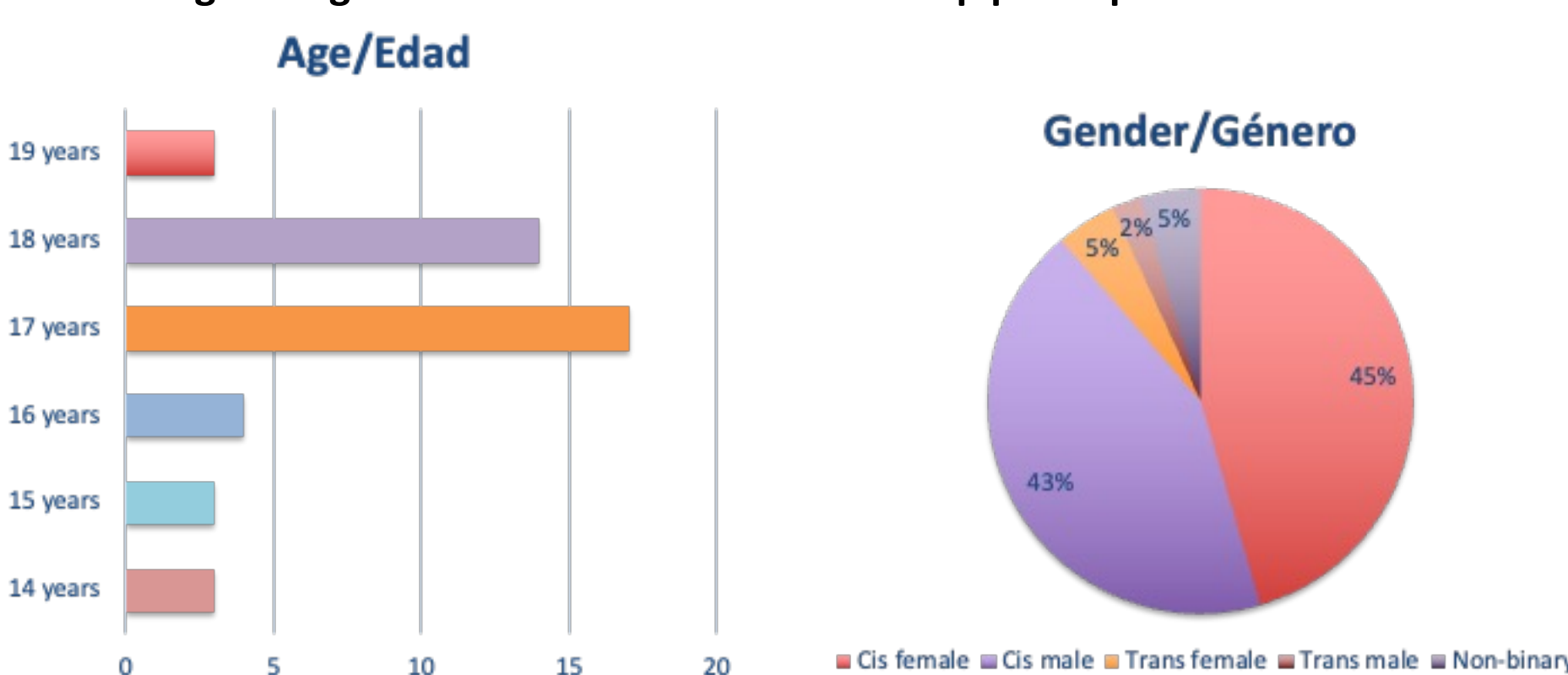
Images: From workshops in South Africa, Uganda and Argentina



Results

In total 46 young people attended the five workshops; 44 of these were adolescent living with HIV, with an additional two young people living with HIV who were 20 years of age.

Chart 1: Age and gender breakdown of all workshop participants

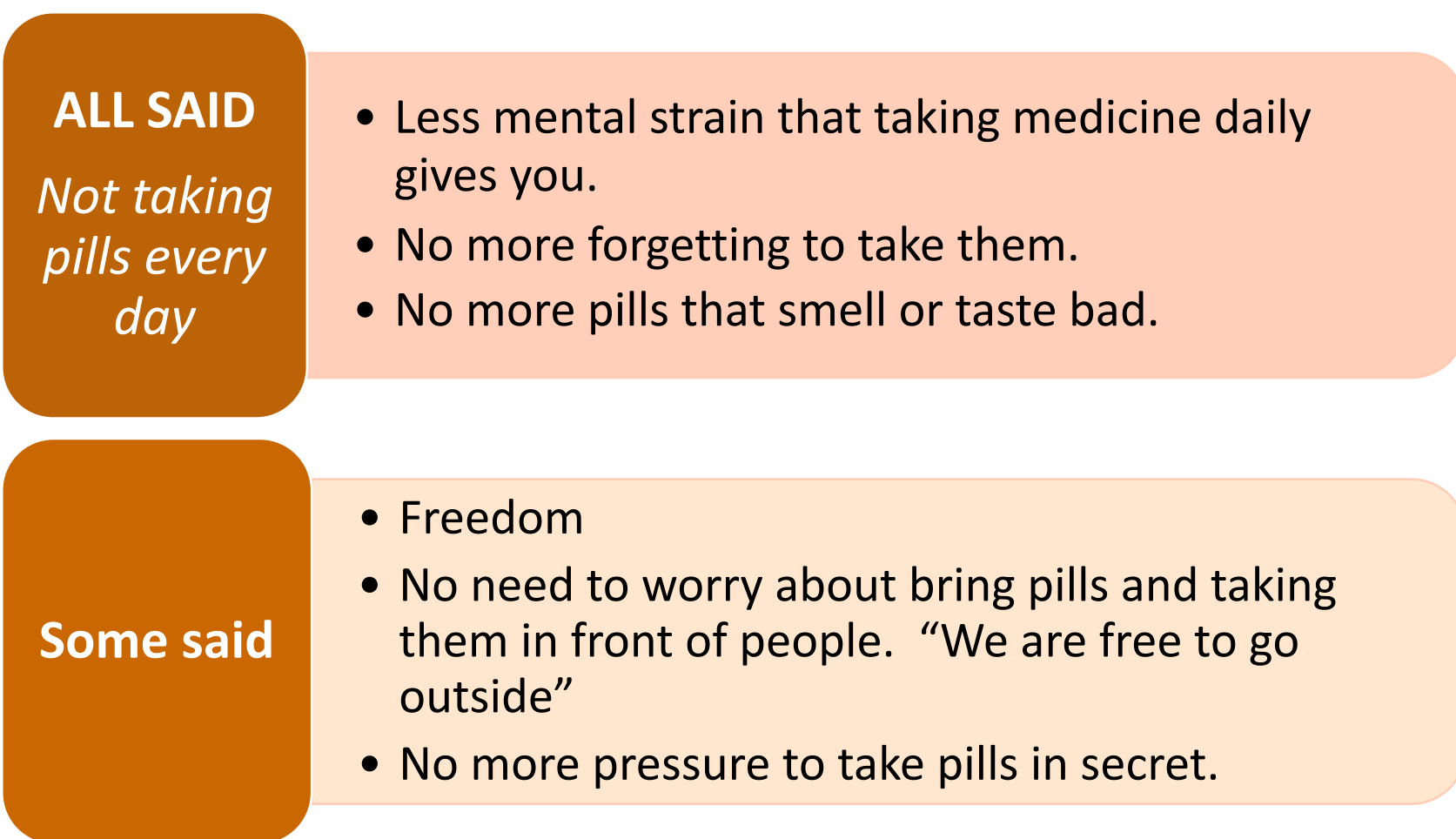


The above charts demonstrate the representation across the workshops, and the intersectional experiences of adolescents living with HIV.

The thematic analysis of the findings presents very clear messages relating to long-acting injectable ART.

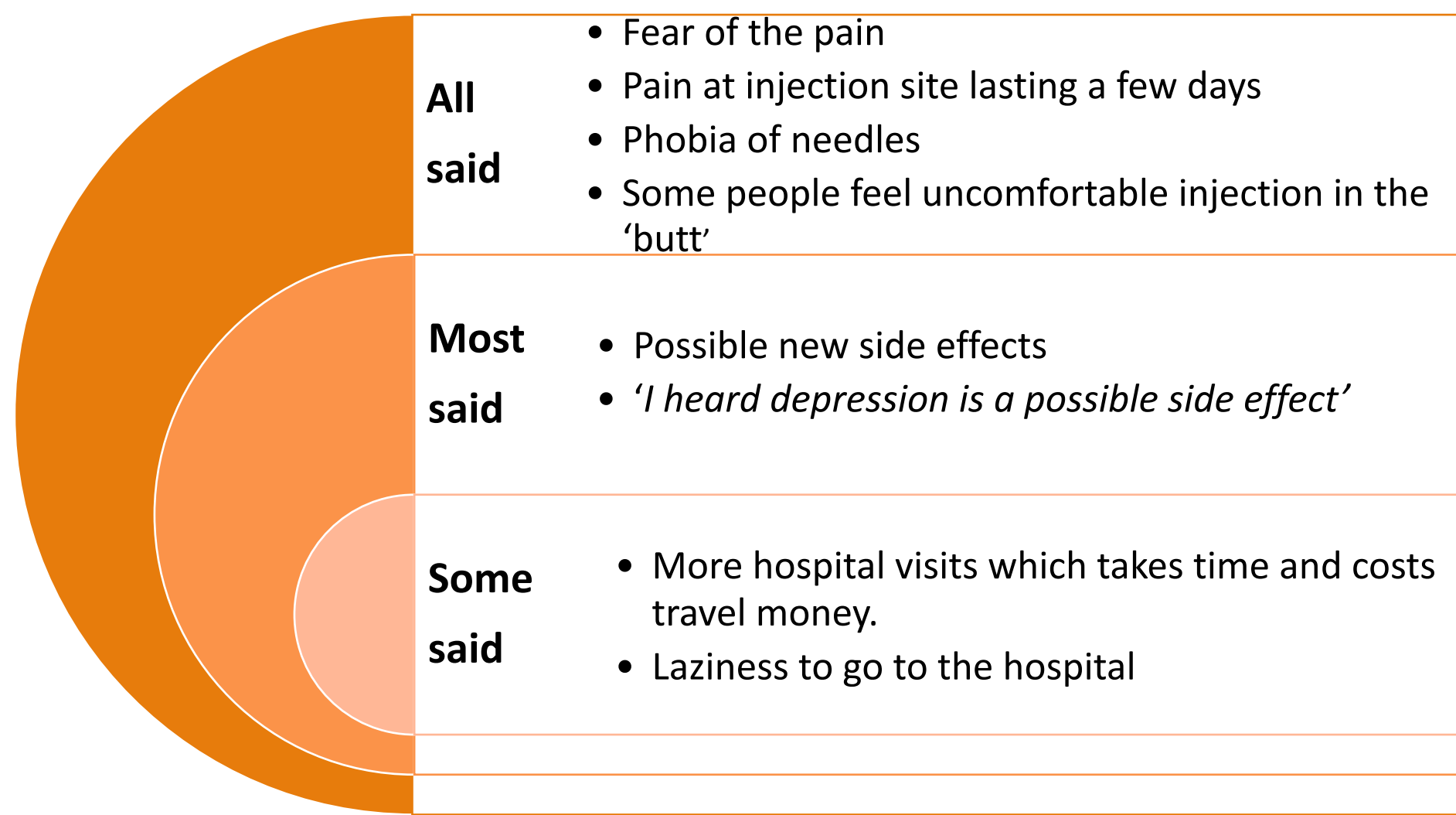
Results: The positives of having access to long-acting injectable ART

This primarily focused on relieving the pill burden and secrecy that young people face.



Results: The worries and fears young people had about long-acting injectable ART

This was predominately about the fear of the possible pain, although unknown side effects were raised and some talked about increased hospital visits and the cost and time these take.



Solutions

The discussion on possible solutions to support adolescents to access long-acting injectable ART were in three themes:

The clinical experience

Training for healthcare providers so they support young people with the injections, showing kindness and empathy ,building trust. Have the option of '**injection buddies**' to support you for your first time. **Injection clinics** which have shorter appointments where you just receive your next injections. Consider **community sites** where injections can be administered to cut down in travel costs and time.

Knowledge and understanding

"People must be educated!" – youth-friendly information in videos and posters to explain how it is administered and how it works.

Social and political support to finance access

Young people want this as a treatment option but acknowledged that for this to happen they needed public and political desire and Governments to ensure availability.

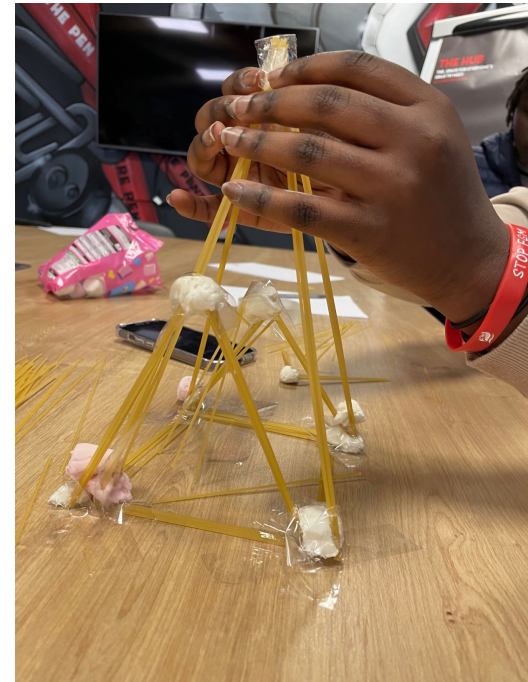
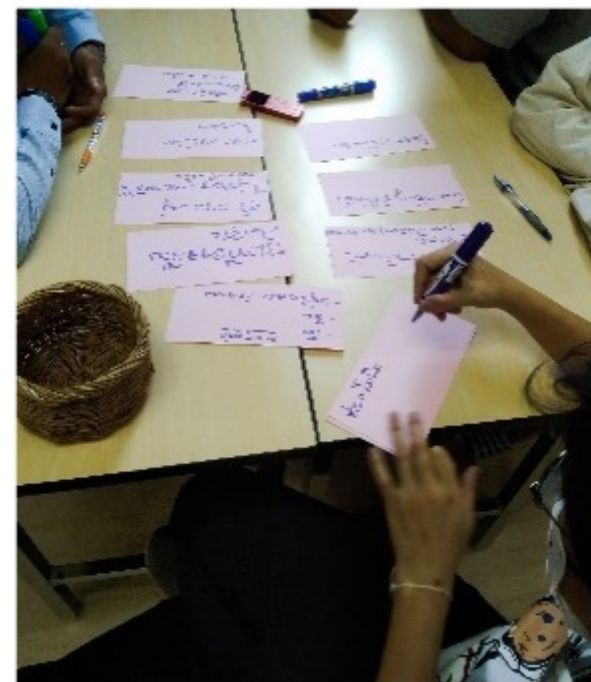
At the end of the workshop the young people were asked again if they would consider taking long-acting injectable medicine, the comparison is shown below.

Chart 3: The results from voting at the start and end of the workshops to whether, if offered, you would want to take long-acting injectable ART.

	START		END	
	Yes/Maybe	No	Yes/Maybe	No
Argentina	7	2	8	1
South Africa	9	1	10	0
Thailand	6	4	10	0
Uganda	10	0	10	0
UK	1	6	7	0

Those who changed their minds expressed that this was due to being given the opportunity to think about their current pill regime, the impacts this has on their lives, verses their initial fear of injections.

Images: From workshops in Thailand and the UK



Conclusion

The model of running workshops across countries and continents worked incredibly well. The workshops needed to take the young people through a journey before discussion could begin, so they had time to learn and consider the emotional as well as practical impacts of ART.

Activities that promoted learning and discussion support the young people to be able to then explore possible barriers and solutions.

Adolescents living with HIV have so much to emotionally manage, navigating adolescents and early adulthood with a chronic health condition that still in too many countries is stigmatised. They are hiding their status from friends and family, hiding their pills and living with the fear someone might find out. Long acting injectables may offer many the opportunity to remove the stress of daily pills, but this does not remove the stigma of HIV, and this must not be overlooked as long-acting medication progresses.

Too many of the young people involved in these workshops shared how little kindness and empathy they experienced in their clinical care. Young people reported the dual stigma they experienced both for living with HIV and for being a teenager. Some reported clinical staff being abrasive, dismissive and abusive. Others reported clinical staff lacking empathy and kindness. They said how important this would be if they felt scared of the injections or felt uncomfortable about the injection site.

This cohort deserve the option of injectable ART and healthcare provision that is understanding and supportive. Without this environment, many will stop attending and not engage with their ART, whether this is pills or injections. As we progress 'Ending AIDS in Children by 2030', both long-acting injectable ART and supportive health services will be critical components in achieving this.

Please visit our website to see the other youth engagement work we do.

Penta has since produced Quality Standards for the ethical and meaningful participation of children and young people in clinical trials and research to support rolling-out of this practice. penta-id.org/patient-involvement-quality-standards/



THANK YOU

All the young people who took part in the workshops and shared their experiences and views. Special thanks for those who then attended the Advisory Group, presenting expertly and generating excellent discussion. The partners and staff their dedicated staff at: Foundation for Studies and Research on Women (FEIM). EnREDando Project; Hillcrest AIDS Centre Trust (HACT); SEARCH Research Foundation (SRF); Mildmay Uganda; Chiva. The Penta Foundation for nurturing and promoting this work. ViiV Healthcare for supporting this initiative.



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Fondazione Penta ETS (Penta) is a leading international research organization in paediatric infectious disease (penta-id.org).