



# Evaluation of youth-friendly interventions for adolescents living with HIV in urban Peru



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HOPE Conference  
March 15, 2022



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# Disclosures

- I have no conflicts of interest.
- Research funding from U.S. National Institutes of Health and Harvard University supported this work.
- Names have been changed.



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# Outline

- Background
- Formative research
- Two pilot intervention studies
  - HIV-related knowledge
  - Transition to adult care
- Lessons learned & challenges





# Adolescent HIV: the numbers

**1.74 million** living with HIV

**170,000** new HIV infections annually

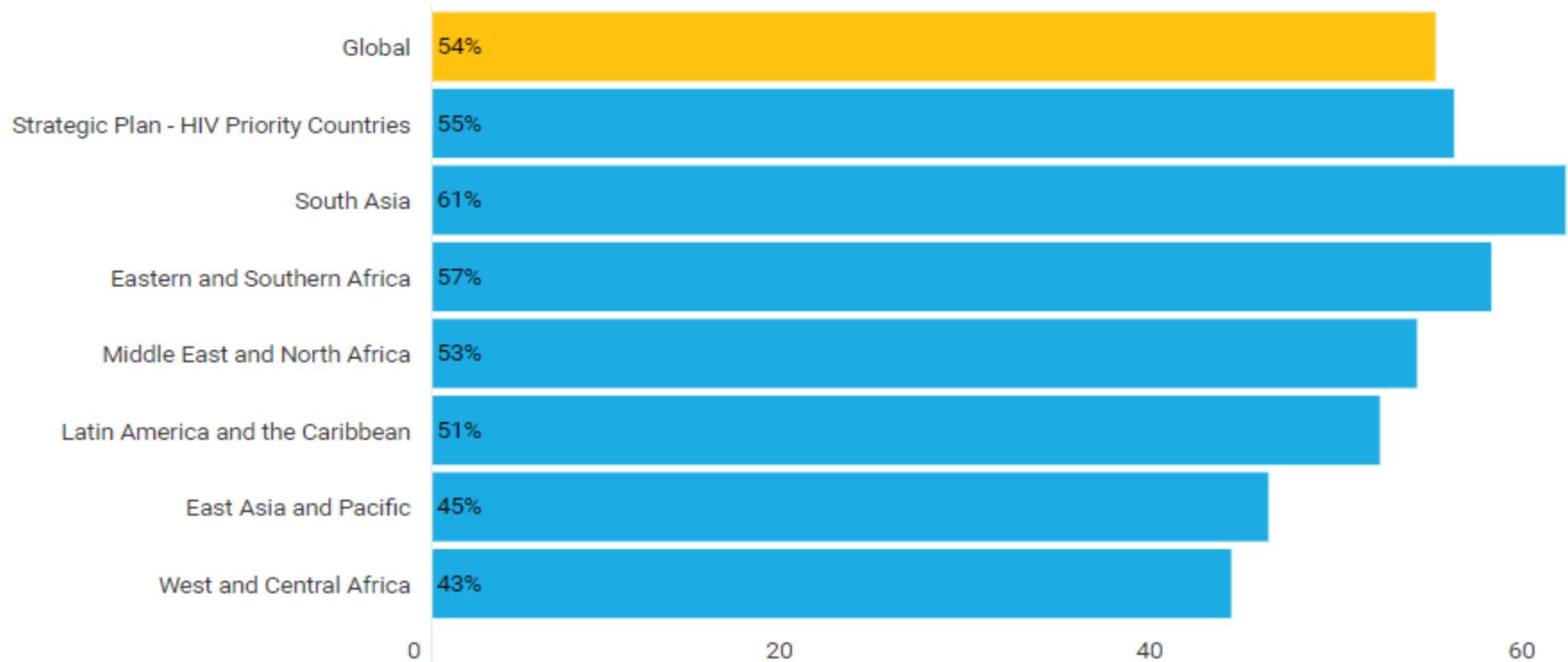
**93** die from AIDS-related causes each day

**34,000** AIDS-related deaths annually



# ART coverage is suboptimal

Antiretroviral treatment coverage among adolescents 10-19 years, by region, 2020



Source: UNAIDS 2021 estimates

# Adherence declines in adolescence



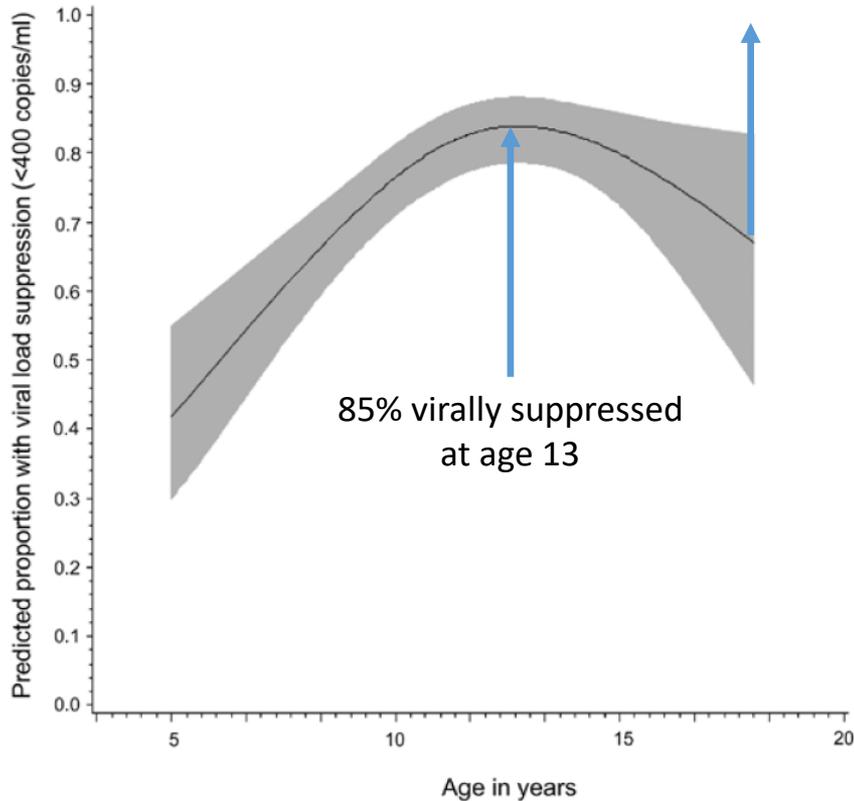
*Interviewer: You're not taking your medication on time, why is that?*

*Milagros (14 yrs): Because I am going out with my friends*



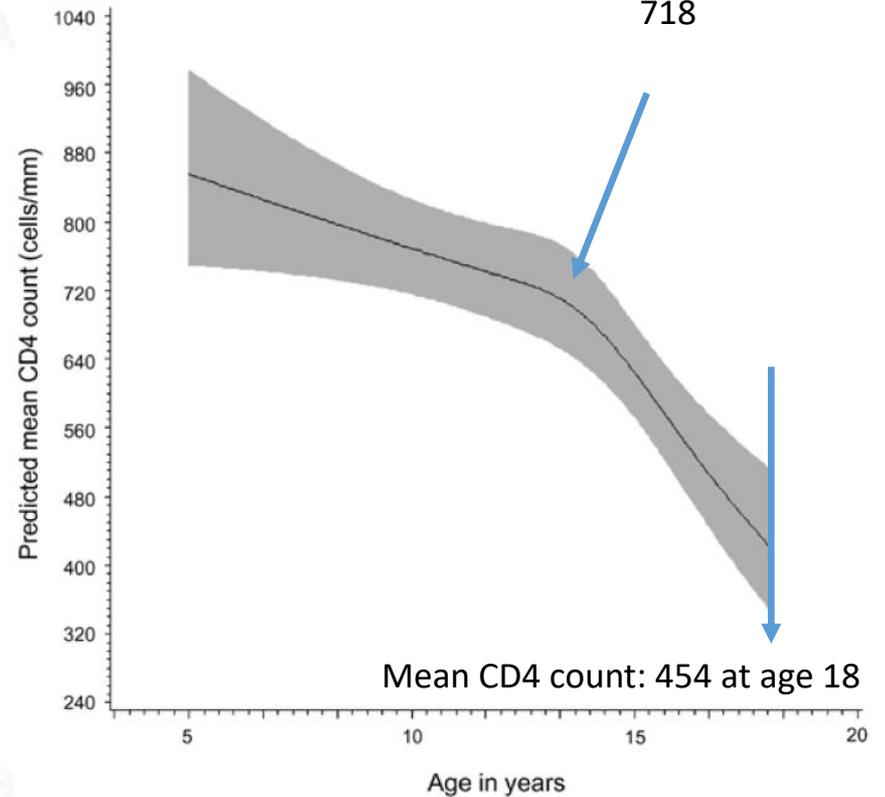
# Treatment outcomes worsen in adolescence

71% of adolescents virally suppressed at age 18



85% virally suppressed at age 13

At age 13, mean CD4 of 718



Mean CD4 count: 454 at age 18

121 adolescents



# Weakened building blocks for health

**PROTECTING ADOLESCENT HEALTH NEEDS YOU!**

-  Families who protect and nurture
-  Healthcare responsive to adolescents' needs
-  Schools that promote healthy development
-  Clean air, adequate water, sanitation and hygiene
-  A transport system that is safe
-  Laws to protect the rights of adolescents





# Major research gaps persist

“There is **a dearth of psychosocial support interventions** to improve adherence and retention in ART among adolescents and young adults with HIV.”

Okonji et al. BMC Public Health 2020

“However, **the paucity of quantitative research** available speaks to the **necessity of more quantitative research studies** and standardization of measures of intervention efficacy.”

Alcon, J Invest Med 2020

“Among adolescents, **current evidence is both sparse and lacking in quality actual**. These findings highlight a pressing need to develop and test targeted intervention strategies to improve adherence among this high-priority population.

Murray et al. PLOS ONE. 2017



# Service delivery research priorities

Interventions to:

- Improve retention in care
- Support pregnant ALWH
- Improve sexual and reproductive health
- Offer psychosocial support

Must be tailored to local context (outside US/Europe) and specific risk groups

RESEARCH FOR AN AIDS FREE GENERATION:

**A GLOBAL RESEARCH AGENDA  
FOR ADOLESCENTS LIVING WITH HIV**



**CIPHER**  
PAEDIATRIC HIV MATTERS





# Must be “Adolescent-friendly”

## Acceptable

Adolescents *are willing* to obtain the services available

## Equitable

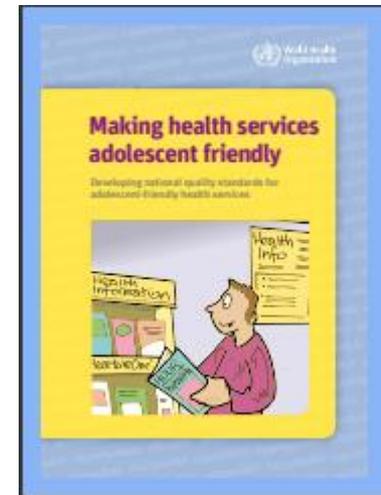
All adolescents, not just select subgroups, are able to obtain the services that are available

## Appropriate

The right health services (i.e., the ones they need) are provided to them.

## Effective

The right health services are provided in the right way and make a positive contribution on their health



# Lima, Peru





# HIV & adolescence in Peru

- 87,000 with HIV
- 60% of new infections occur in young MSM / TGW
- 2004: cART in public clinics
- Pregnancy in adolescence common (17%)





# 2015: Lima, Peru



*Dr. Lenka Kolevic  
Chief, Infectious Disease Service  
Director, HIV Program*



*Instituto Nacional de Salud del Niño, Lima, Perú*

- National pediatric referral center
- Majority of perinatally infected children treated here



# Needs assessment

- Qualitative interviews  
(10 caregivers, 5 health providers)
- Chart review of adolescents  
currently on cART (N=121)
- Social support groups (qualitative  
data source; 32 adolescents)
- Quantitative interviews (ACASI,  
N=32) adherence, health behaviors



*Study nurses Jessica and Ingrid  
program the ACASI data collection  
tool.*



# Overview of adolescents (N=121)



33% with history of TB



27% detectable viral load



28% orphans of both parents



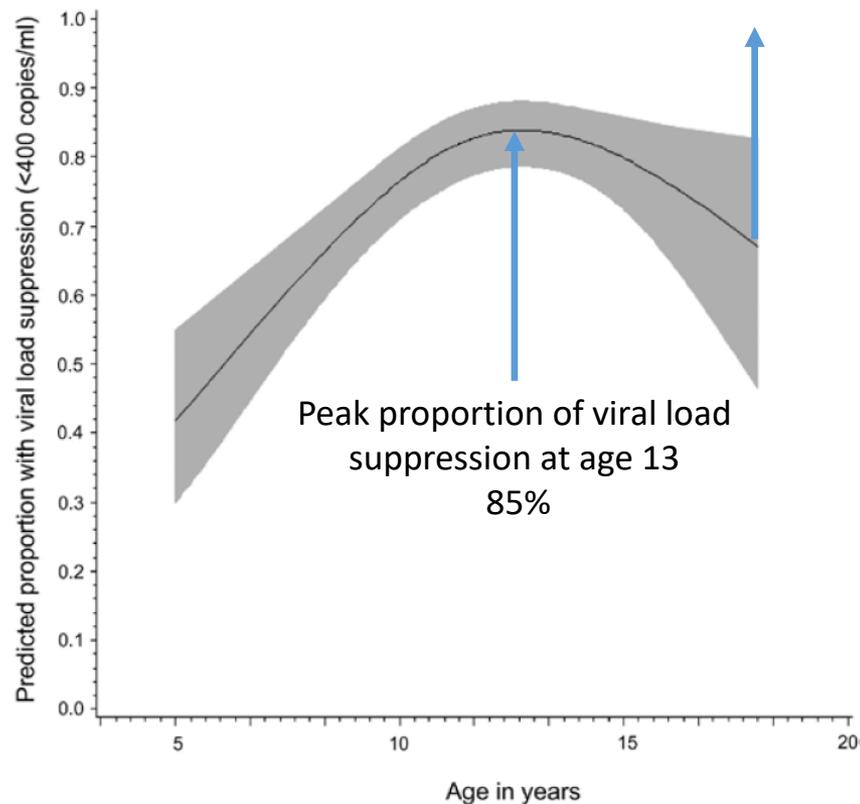
18% living in a group home



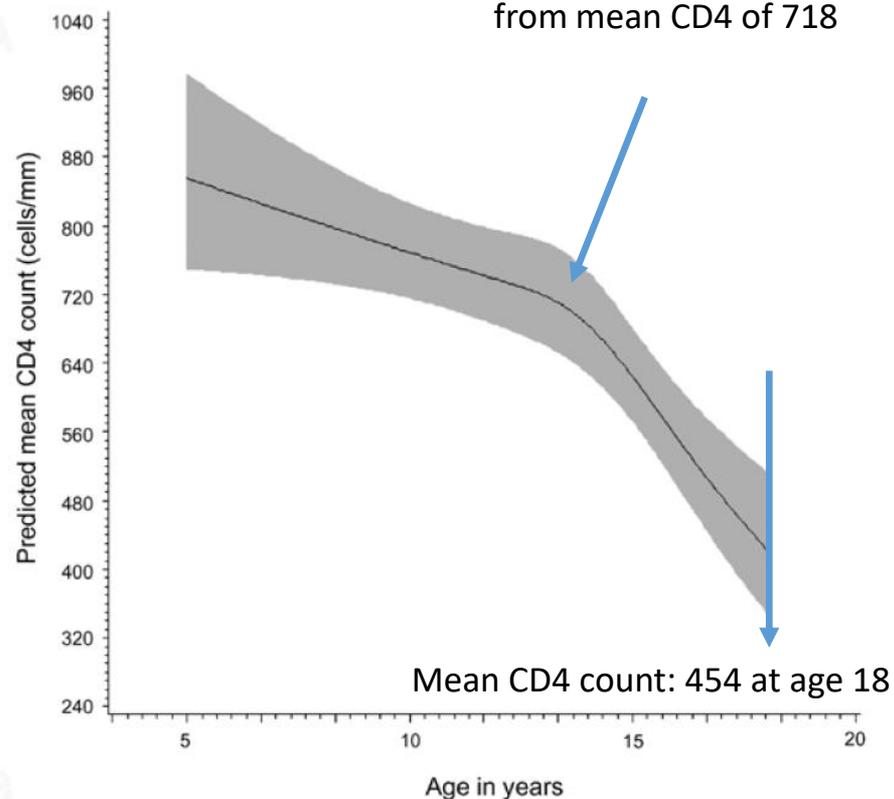
*Milagros Wong: Study Coordinator,  
Qualitative Researcher*

# Declining viral suppression and CD4

71% of adolescents virally suppressed at age 18



Sharp decline at age 13 from mean CD4 of 718



121 adolescents, 1,494 viral loads, 2,406 CD4 cell counts

# Adherence barriers and facilitators

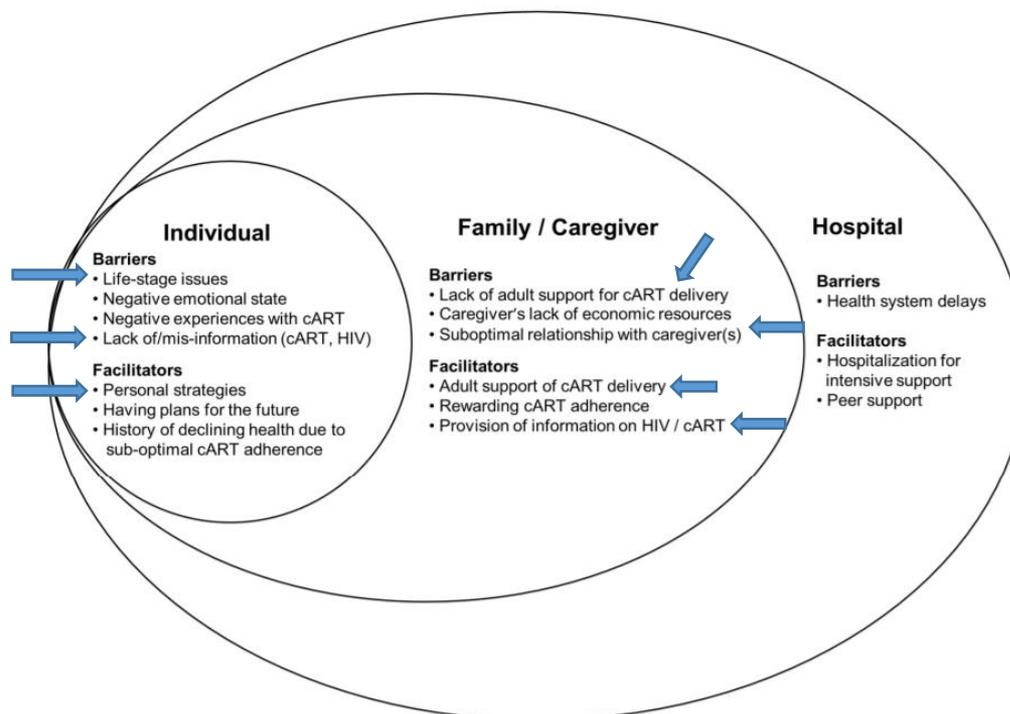


Fig 1. Social ecological model of barriers to and facilitators of antiretroviral cART adherence among Peruvian adolescents.



# Gaps in HIV-related knowledge

*Facilitator: You take your medication at 8 on the dot, and if you miss it?*

*Carlos: Then I don't take it.*

*Gustavo: It's not even worth it if it's too late since it's not going to count, it's not going to count, and you'd be taking them for nothing, right?*

Carlos, 13; Gustavo, 15

*My questions would be about how to take the medicines at the exact hour, what to eat, tips, guiding me.- Blanca, 17*

*Gustavo: So, I take [the pills] in the morning before going to school. I take 13 pills. . . no, 14.*

*Luz: He takes pills. What he doesn't take in the morning he takes at night. That's what I used to do.*

Gustavo, 15; Luz, 15

# An educational rap video





# An educational rap video

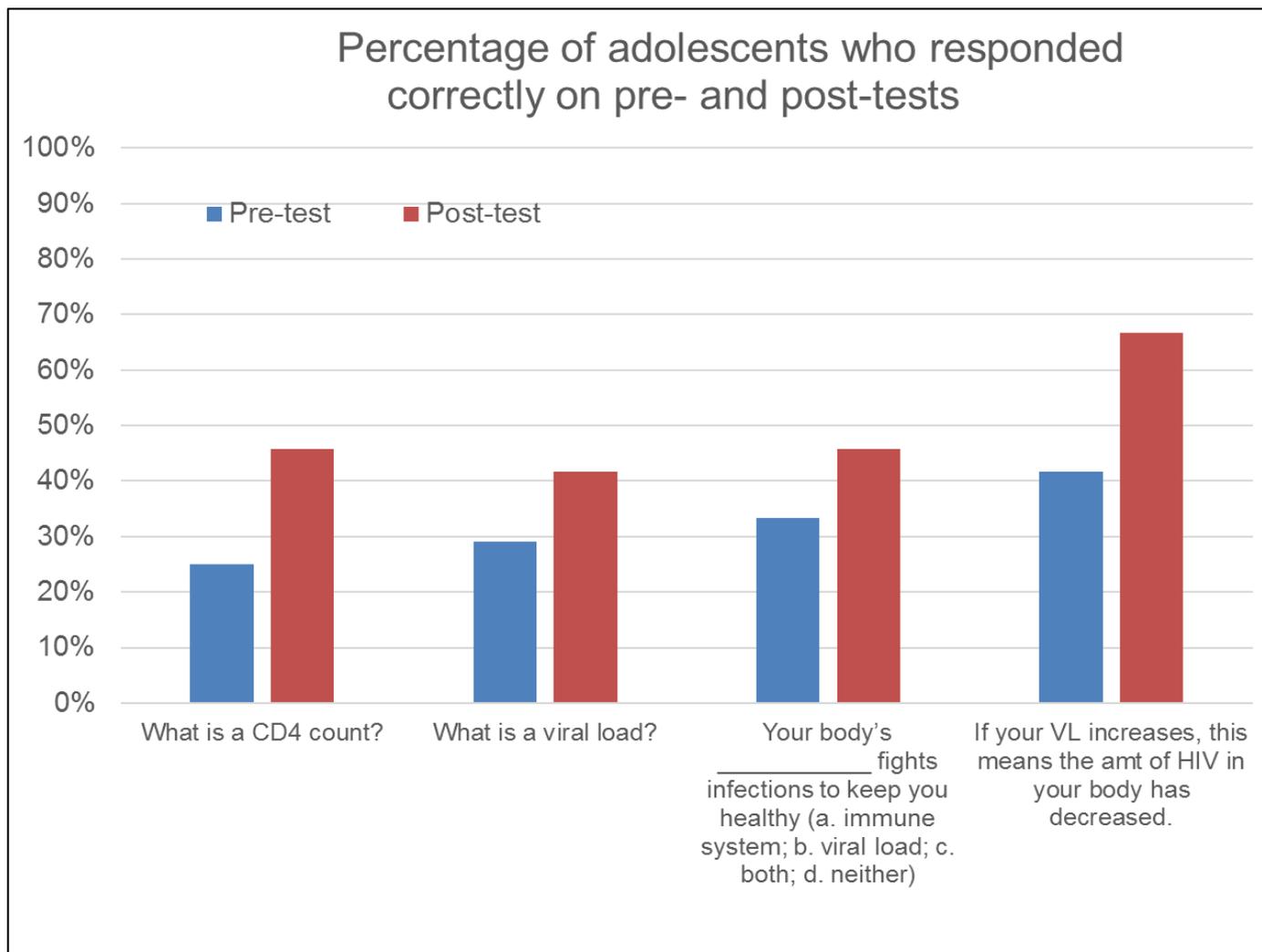


Instagram handle: [dime.peru](https://www.instagram.com/dime.peru)

*Beats credit: Tú No Vive Así Arcángel & Bad Bunny*



# Modest improvements in knowledge





# Adolescent perspectives

*[I like it] because it teaches me and I am going to know and learn and listen and it's not boring like a brochure or a talk.*

*-- Female, 16-17 years*

*Adolescent (13-15 years): So before the video I thought that CD4 was, for example, the virus that was in our body and that viral load was the good one.*

*Researcher: And now, from the video, what did you understand?*

*Adolescent: That the CD4 is our cells that protect our body.*

*Researcher: And viral load?*

*Adolescent : The virus that is acting.*

*It all depends on us, that we take care of ourselves and improve our health. It all depends on whether we take care of ourselves, take our medications when we should...this is what it teaches. What I got out of it the most is that.*

*-- Male, 13-15 years*



# Provider perspectives

*... Even though they already know about their illness, and they know what we tell them at all of their appointments, what is always missing is someone to tell them in their own language.*

*-- Physician*

*I am a proponent of giving them other means [of learning] that are age appropriate, such as music that they hear every day. It's important, no? To have someone that is your peer talk to you and sing to you. [The adolescents] probably feel like they are alone in having the disease.*

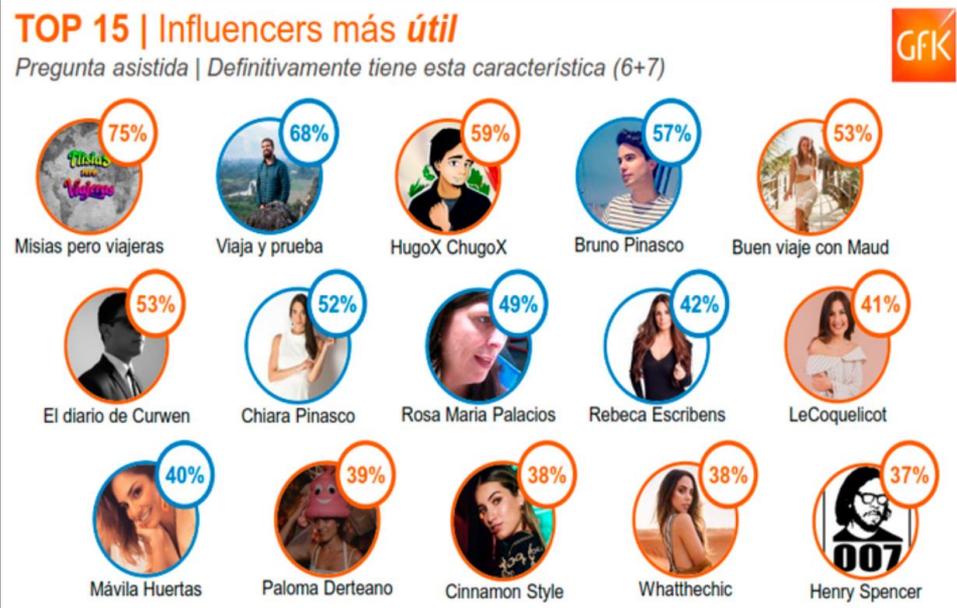
*-- Physician*

*...because there are images of here, of Peru, where they recognize. In other words [the setting] is not a foreign place where they say there, "yes", but here, "no". Or that in those places, yes you are going to live, but here you are not. That's not the same as saying, "Here, there is a solution for you."*

*-- Nurse*



# Next steps





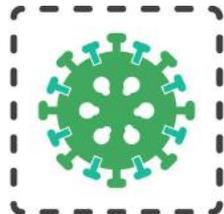
# Transition to adult HIV care



New provider / facility, insurance issues, total independence



Missed clinic visits, lower adherence



Decreases in CD4, unsuppressed viral loads, attrition from care



# Retention and viral suppression among newly-diagnosed adolescents (2017- March 2020)\*

Time	N	Outcomes n (%)			
		Retained, VL suppression	Retained, VL data	Retained, detectable VL	Not retained
12 months	190	79 (42)	54 (28)	22 (12)	35 (18)
24 months	121	30 (25)	12 (10)	13 (11)	66 (55)
36 months	85	6 (7)	4 (5)	4 (5)	71 (84)

\*Unpublished data



# Time-limited accompaniment intervention



## Health system navigation + individualized adherence support

- Health insurance
- Accompaniment to clinic appointments
- Resolution of acute needs
- Transport
- DOT, as needed

## Health-related knowledge, skills, and psychosocial well-being

- Social support groups
- Education sessions
- Mental health screening, referral

9-month duration:  
6-months intensive + 3 months taper

# Adolescents, 15-21 years (N=30)

Range of transition experiences

- Early childhood & new diagnosis
- Same vs different facility
- Pregnant women
- Those lost from care



Three icons stacked vertically: a shield with a lion, hands, and a circular arrow.

# Data collection

## Quantitative

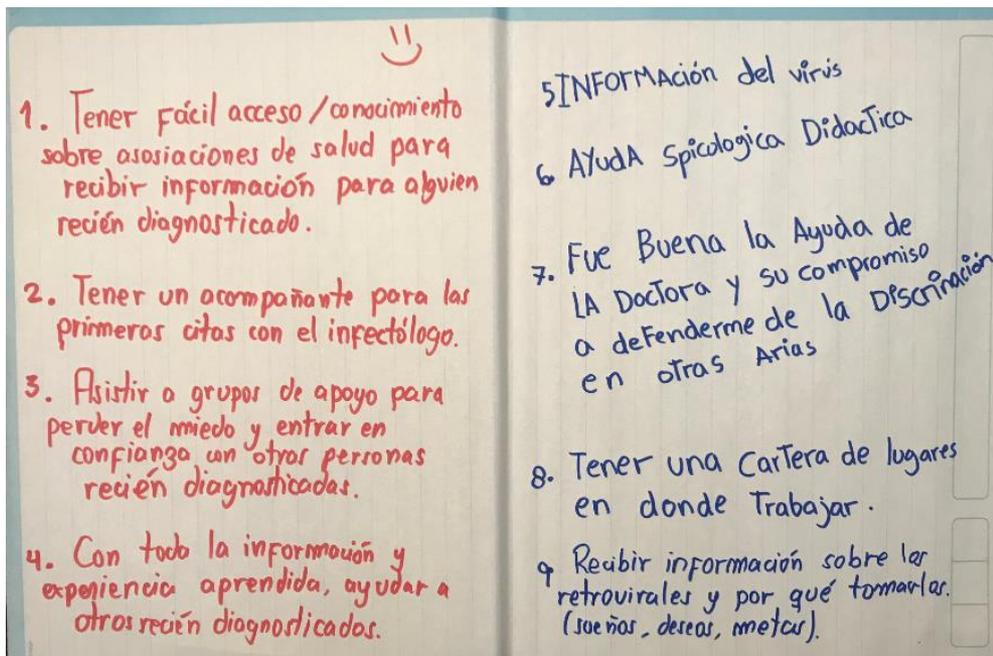
- Feasibility indicators
- Baseline, 6, 9, 12 months
- Psychosocial (NIH toolbox), transition readiness (Am I on TRAC), adherence (self-report)

## Qualitative

- Participants, stakeholders



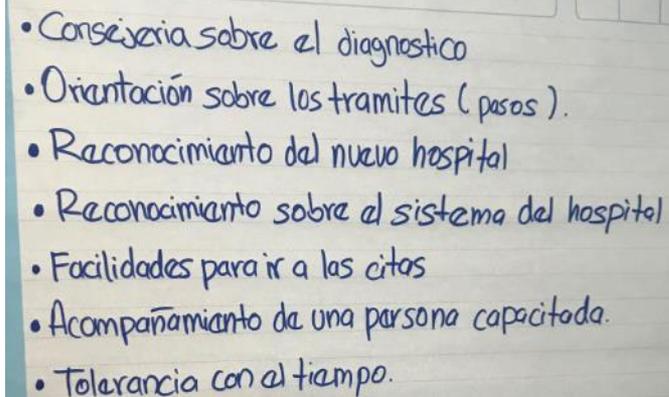
# Youth Advisory Board

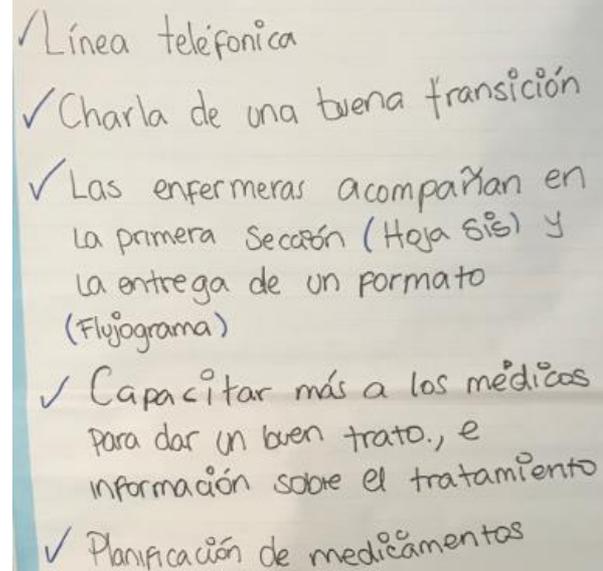
- 
1. Tener fácil acceso / conocimiento sobre asociaciones de salud para recibir información para alguien recién diagnosticado.
  2. Tener un acompañante para las primeras citas con el infectólogo.
  3. Asistir a grupos de apoyo para perder el miedo y entrar en confianza con otras personas recién diagnosticadas.
  4. Con toda la información y experiencia aprendida, ayudar a otros recién diagnosticados.
5. INFORMACIÓN del virus
  6. Ayuda Psicológica Didáctica
  7. Fue Buena la Ayuda de LA DOCTORA y su compromiso a defenderme de la discriminación en otras áreas
  8. Tener una Cartera de lugares en donde Trabajar.
  9. Recibir información sobre las retrovirales y por qué tomarlas. (sueños, deseos, metas).

Brainstorming activity to identify factors that could facilitate the transition to adult care

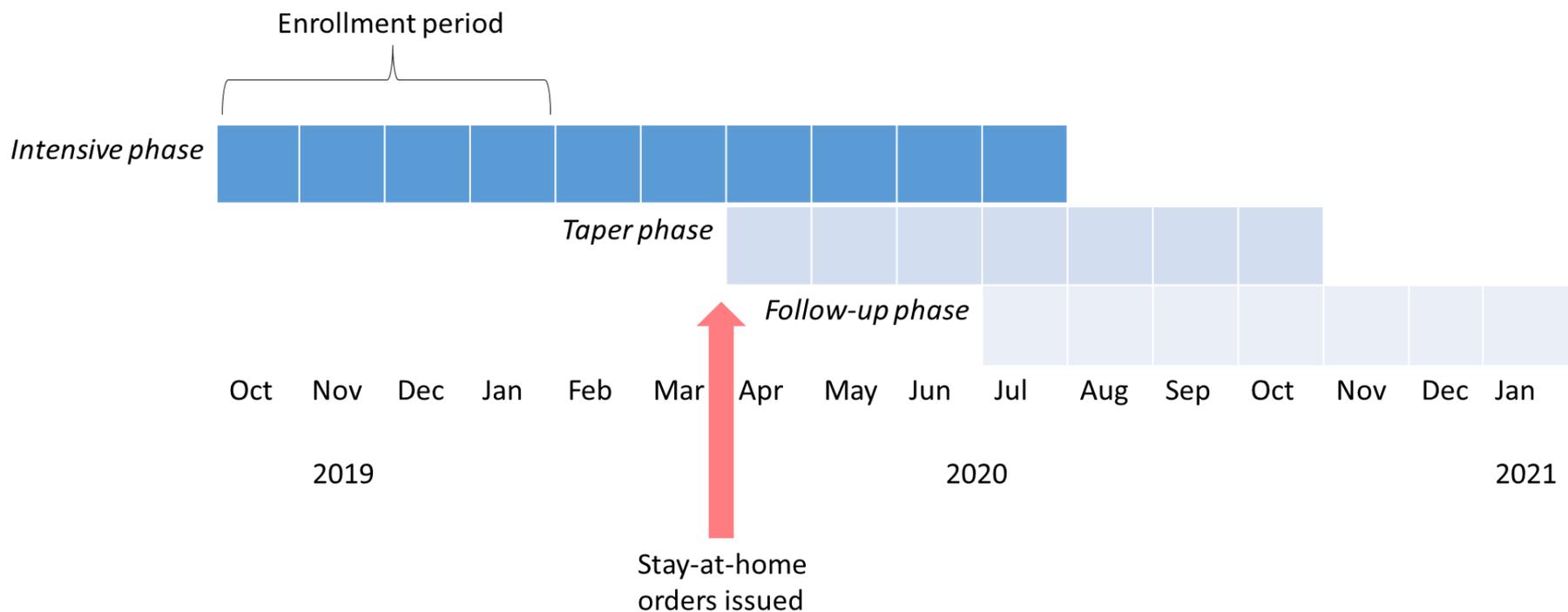


PASEO

- 
- Consejería sobre el diagnóstico
  - Orientación sobre los tramites (pasos).
  - Reconocimiento del nuevo hospital
  - Reconocimiento sobre el sistema del hospital
  - Facilidades para ir a las citas
  - Acompañamiento de una persona capacitada.
  - Tolerancia con el tiempo.

- 
- ✓ Línea telefónica
  - ✓ Charla de una buena transición
  - ✓ Las enfermeras acompañan en la primera sección (Hoja 515) y la entrega de un formato (Flujograma)
  - ✓ Capacitar más a los médicos para dar un buen trato, e información sobre el tratamiento
  - ✓ Planificación de medicamentos

# Implementation & COVID-19



# Participant characteristics

Characteristics	All participants N=30 (%)	Early childhood infection N=19 (%)	Recent infection N=11 (%)
Age, in years, median [IQR]	19 [18-20]	19 [18-20]	19 [18-20]
Female assigned at birth	12 (40)	11 (58)	1 (9)
Female gender identity	13 (43)	11 (58)	2 (18)
Identifies as MSM	10 (33)	1 (5)	9 (82)
CD4 count, median [IQR]	544 [349-615]	553 [381-608]	535 [331-608]
Suppressed viral load*	--	9 (69)	--
Venezuelan nationality	5 (17)	1 (5)	4 (36)
At least one living parent	19 (63)	8 (42)	11 (100)
> 1 traumatic life event	21 (70)	11 (58)	10 (91)
Past sexual abuse / assault	12 (40)	5 (26)	7 (64)
Pregnant	4 (13)	3 (16)	1 (9)
Homeless	4 (13)	4 (13)	0 (0)
Depression, any severity	22 (73)	14 (74)	8 (73)

\* Among 13 adolescents on ART at transition

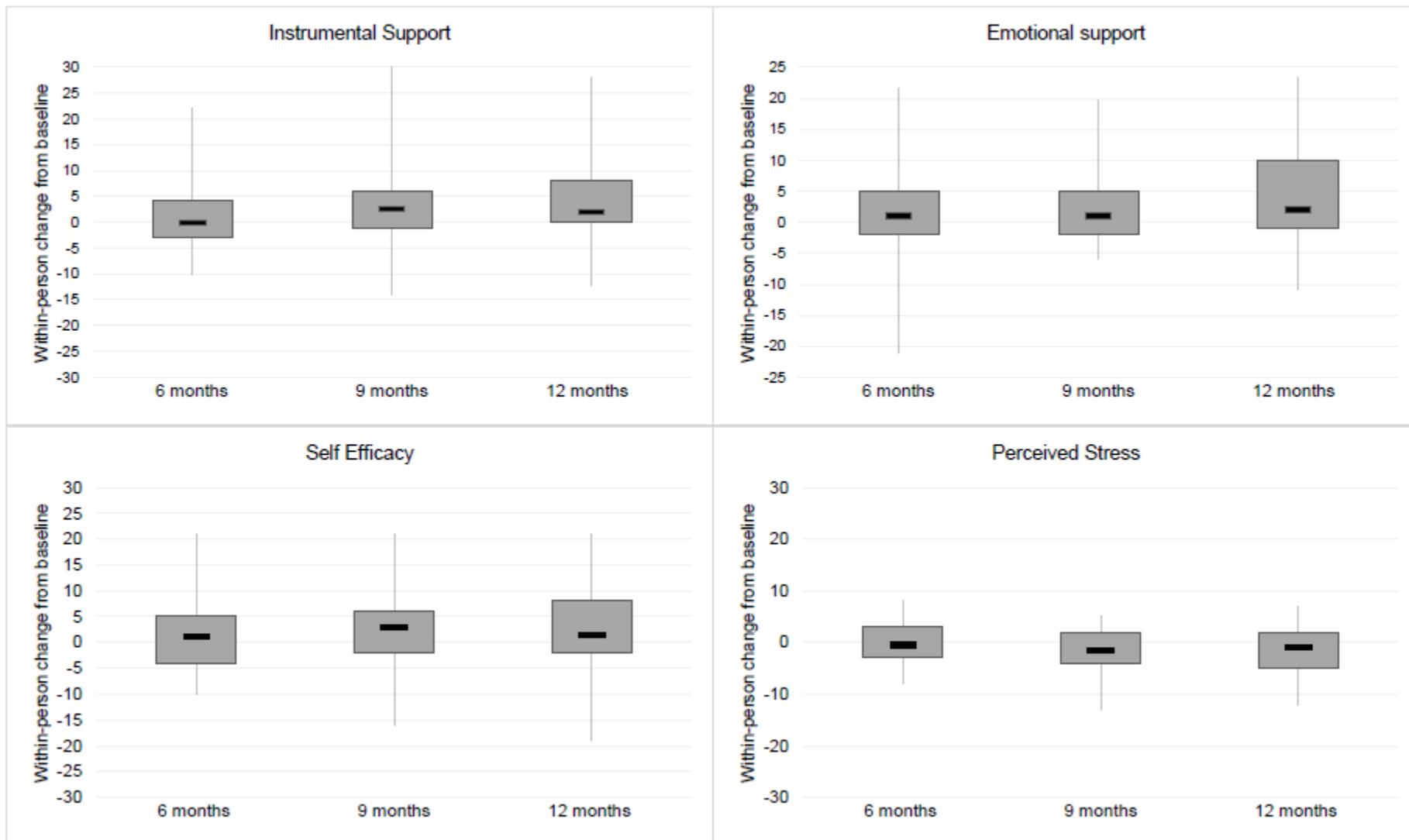


# Results: Feasibility indicators

- 36 invited, 30 accepted
- 8 received & completed DOT
- 90% attended  $\geq 1$  support session
- 93% participated in  $\geq 1$  virtual session
- All retained at 12 months (in study & ART)

# Results: Psychosocial outcomes

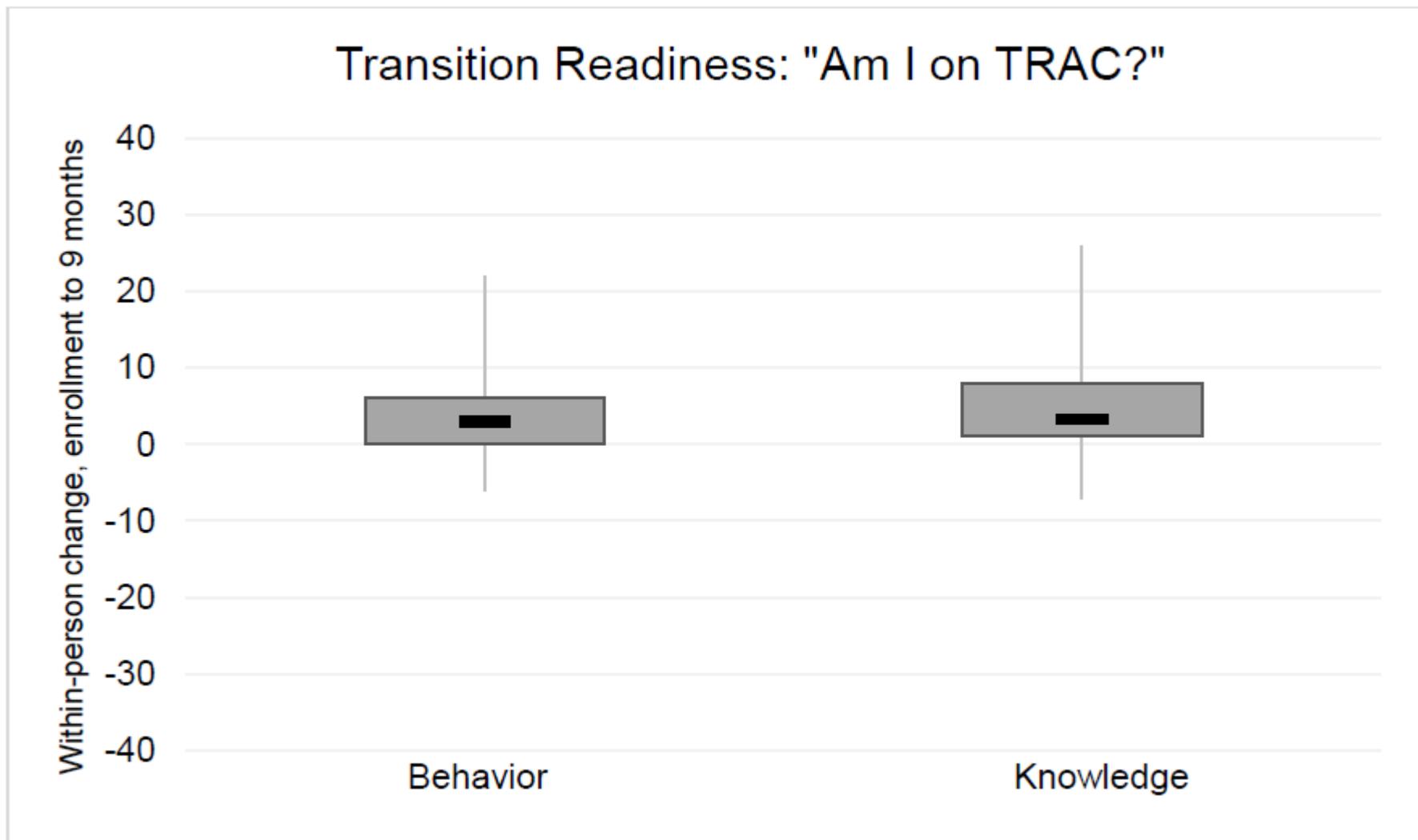
Within-person change from baseline, after intensive & taper phases & post-intervention



\*Boxes represent 25th and 75th percentile

# Results: Transition-readiness

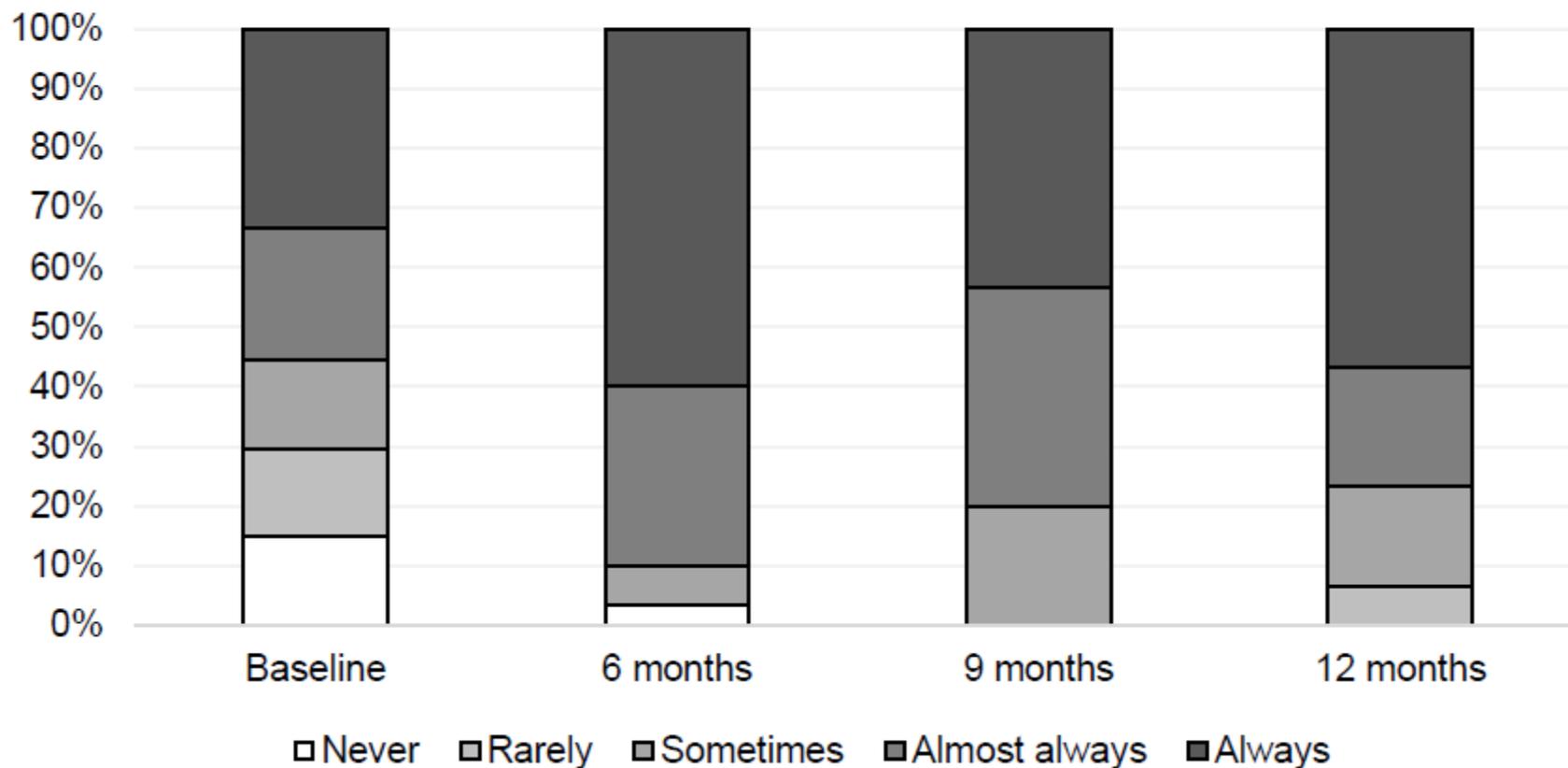
Within-person change from baseline to 9 months



\*Bars represent 25th and 75th percentile

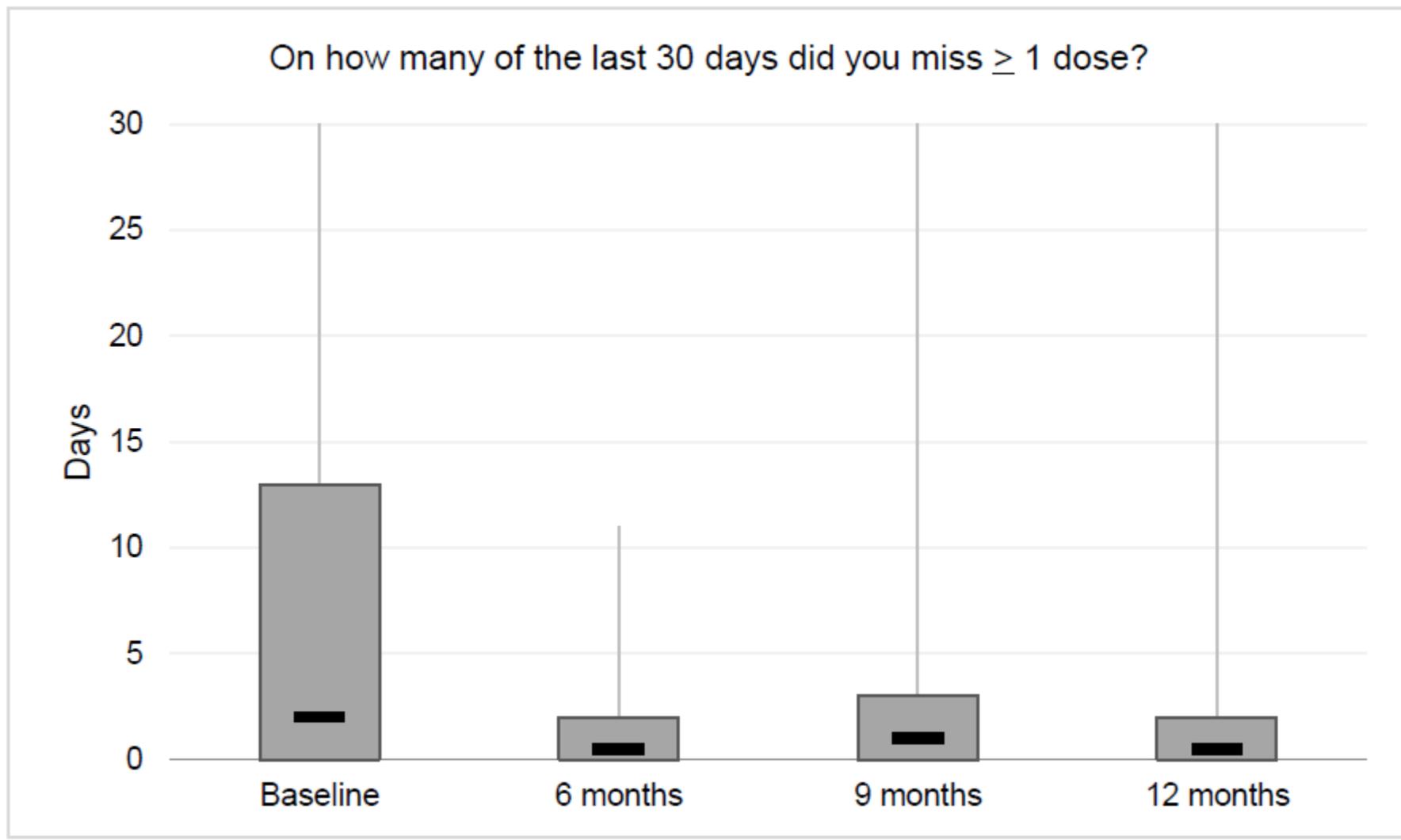
# Self-reported adherence, last 30 days

How often did you take your medications correctly?





# Self-reported adherence, last 30 days





## In their words...

*"I feel safe, confident, and able to complete the administrative processes and treatment on my own."*

*"When I started with PASEO, my viral load was [terrible], I was depressed, but I feel I have improved a lot thanks to PASEO."*

*"If I had not enrolled in PASEO, I would still be without treatment, of that I am sure."*



# In their words...

*“Outside of her job [my health promotor], which was to accompany me to the hospital and see that I take my treatment, apart from all of that she gave me her friendship. She gave me the confidence to trust her and ask her advice and talk... about things related to treatment and why I did not want to take my medications.”*

*“I am very thankful because [my health promotor] was there with me even though I refused to go back on treatment. She was there with me to this day and not I am undetectable and it is all because of her because she was there for me, not only as a worker but as a friend.”*





# Lessons learned



- Social support, education/coaching sessions; health systems navigation most impactful
- Health promoters: supportive, nonjudgmental allies and advocates.
- Similarities among diverse adolescents are powerful
- Depression (mild to moderate) common
- Further tailoring required to reach young TGW



# Facilitators



- Committed, multidisciplinary team
- Mixed methods (qualitative and quantitative)
- Youth advisory board



# Challenges

- Individualization versus sustainability
- Adolescent-friendly study designs
- Staff burn-out
- Cases of extreme need

Thank you for your attention

Questions?

Molly\_franke@hms.harvard.edu





# Impact of COVID-19 in ALWH

- Challenges with public transport
  - Limited (long waits, walks)
  - Fear of bringing COVID-19 home to elderly loved ones
- cART shortages
- Financial difficulties, uncertainty about the future
- Fear of involuntary disclosure