Science With, Not On:
The Power of Partnership in Community-Engaged Research
Strategies for Engagement at Any Budget

Claire Berman, Amanda Flores, & Kimbrae S.

For the Pediatric HIV/AIDS Cohort Study

Harvard T.H. Chan School of Public Health

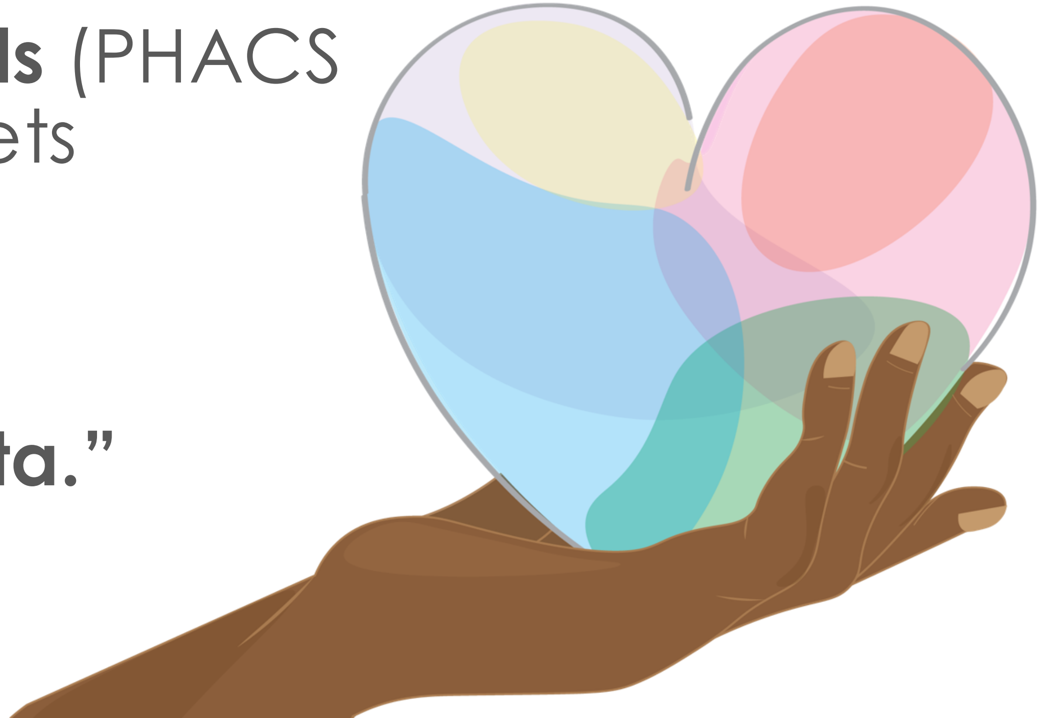
Interdisciplinary Association for Population Health Science | March 27, 2025

ICE BREAKER

What is the **seed that brought you here today**, whether personal or professional?

Our Goals Today

1. **Discuss the benefits** of community-engaged research
2. **Explore a tiered approach** for community engagement based on budget and capacity
3. **Learn about two successful models** (PHACS and HOPE) at two different budgets
4. Lessons learned and **takeaways**
5. Discussion and idea sharing
6. **"Don't forget the human in the data."**



Why does community engagement matter?

Historical lack of engagement and its **consequences**:

- Deep **mistrust** of research
- Outcomes **don’t reflect full spectrum** of experiences with a health condition
- Outcomes **don’t translate clinically for all patients**
- **Wasting resources** on materials that don’t land

Benefits of **community partnership:**

- **Increased trust** in research process
- **Establishing new narrative** for people of color in research
- **More relevant research** questions and sensitive data collection
- Improved **data quality**
- **Culturally relevant research**, outcomes, and resources

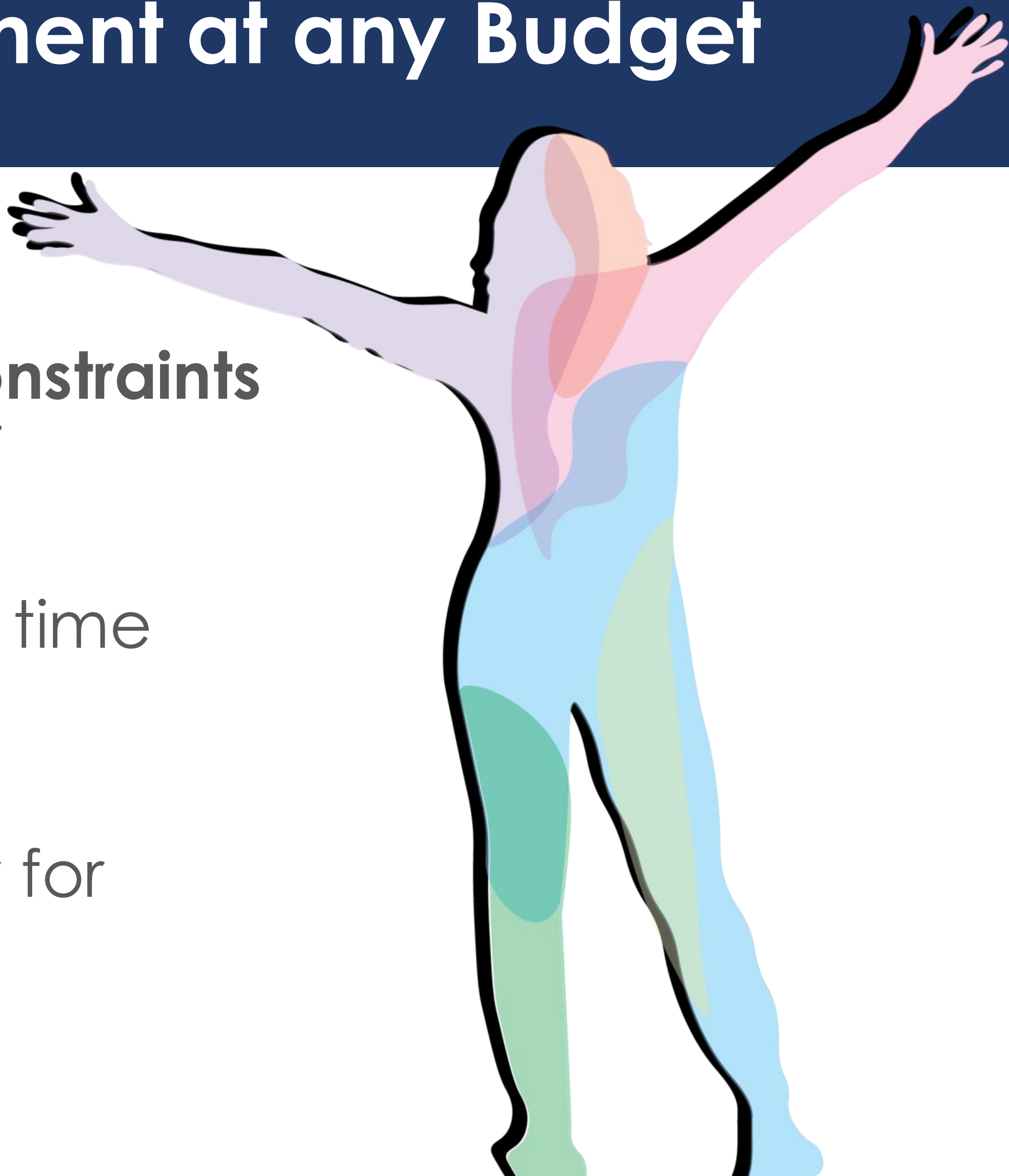
Question For You

What makes community engagement *meaningful* and not just a checklist item?

Goals of community engagement

- Bi-directional communication and partnership between researchers and community members
- Co-shape the research so it's driven by issues experienced by the community
- Who is "community"?
  - People most affected by what you are studying, and who you hope hope will benefit from your research
    - Study participants
    - People w/ lived experience but not in your study
    - Family members/partners of study participants
    - Social workers or clinicians
    - Others who are impacted

The Tiered Model: Engagement at any Budget



- **Recognizing different budget constraints** and different types/sizes of grant mechanisms
- How to **scale engagement** over time
- Getting **creative with resources**
- Start with what there is **capacity** for
- **Flexibility** is key

Tier 1: Foundational Engagement (lower-budget options)

- **Key Strategies:**
  - **Dedicate 20-40% of existing staff member's salary to community engagement**
  - Community Advisory Board (CAB) meet every 1-3 months (virtual or in person)
    - *If you have clinics, do they have CABs who can send reps to yours?*
    - *Is there an existing institutional CAB you could work with / visit?*
  - **Transparent communication** to wider participants and clinical sites (i.e., bi-annual newsletter with study updates)
  - **Donated gift cards as remuneration** (movie theater, zoo, etc.)
  - Utilize **existing institutional support** as much as possible
    - *Media/comms office, professional development opportunities, interns*

Tier 1: **Key Goals**

- **Establish relationships with community members**
  - These could be study participants, members of other CABs, social workers, family members, etc.
- Build initial **trust and dialogue**
- Provide a **direct feedback loop** to engage community in highest priority areas (given limited time and resources)

Tier 2: Enhanced Engagement
(mid-level budget)

- Key strategies (added from Tier 1):
  - **Dedicate part-time of more than one staff member** (i.e., have co-liaisons)
  - Community Advisory Board (CAB) meet every month (virtual or in person)
    - *Gift cards or small stipend for attending monthly calls*
  - **Community Task Force (3-5 members)** with higher engagement throughout the month to work on tasks
    - *Monthly stipend for set # of hours of work per month*
    - *Possible to engage multilingual participants (if bilingual staff)*
  - Hold **annual in-person retreat**, if possible
  - **Engage creative professionals** (graphic design, film) even if only in consultant capacity

Tier 2: **Key Goals**

- **Sustain community participation** and familiarity for the full arc of your study
- **Community members are full members of study teams**
- **Co-develop** study aims and participant materials with community members
- **Provide input for research proposals** for how to use data collected in study
- **Develop selected creative resources** in collaboration with community

Tier 3: Comprehensive Engagement
(high budget, full integration)

- Key strategies (added from Tier 1 + 2):
  - **1-2 dedicated full-time staff for community engagement, health communication, and graphic design**
    - *Possible additional part-time staff*
  - Possibly multiple CABs depending on participant population
    - i.e., young adults vs older adults, multiple languages
  - **Community Task Force (5-12 members)** with higher engagement throughout the month
    - Monthly stipend for set # of hours of work per month
  - **Develop cross-functional team (like Health Education and Communication Committee) of researchers and community**
  - Apply for grant funding as a Core or Center, or from PCORI
  - **Co-lead research with community members**

Tier 3: **Key Goals**

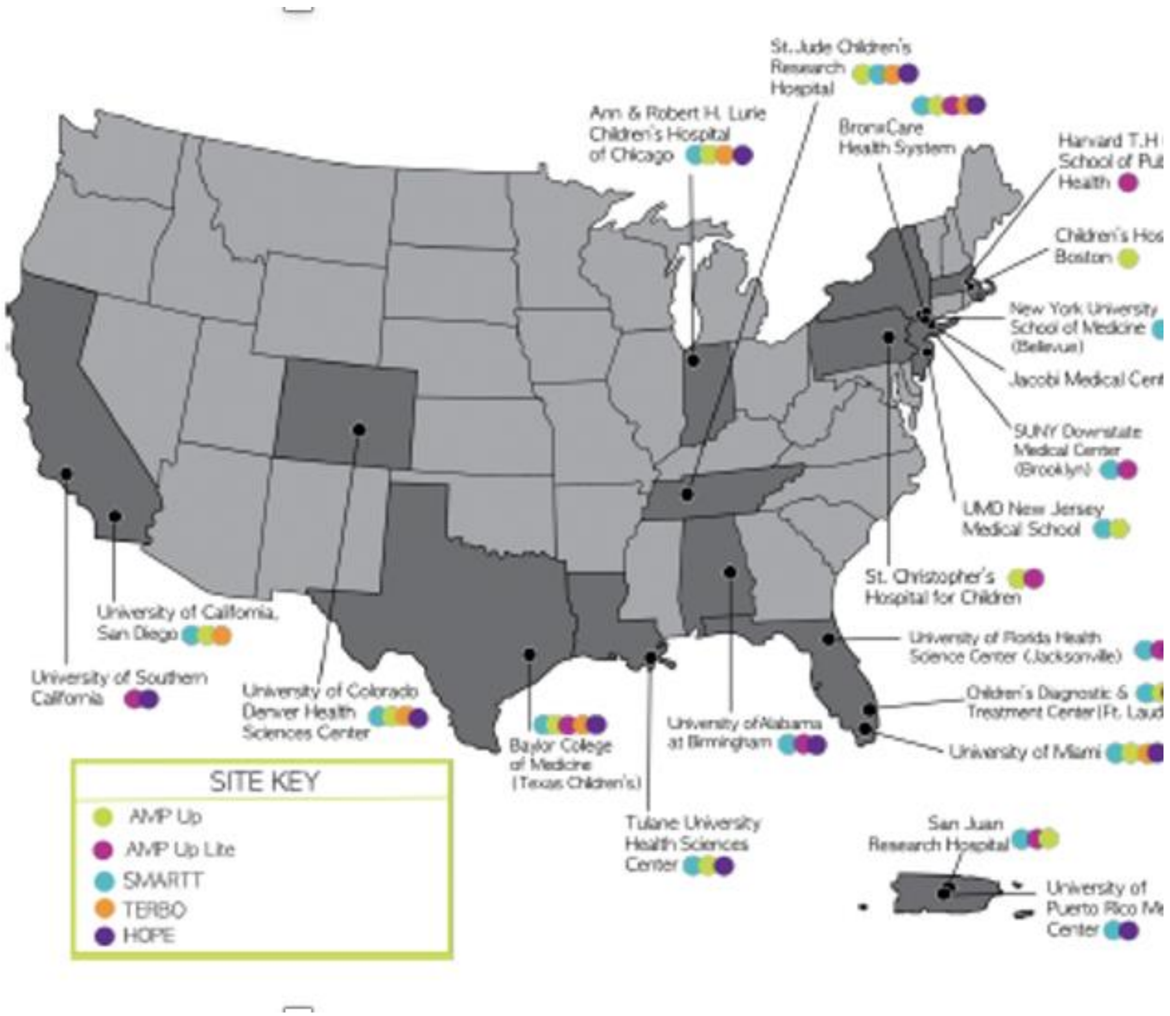
- Use a **shared-decision making model** for research planning and implementation (aims, participant materials, processes)
- **Embed community members on leadership** and working group teams (i.e., voting members)
- **Review all research proposals** for analyzing data collected in study
- **Develop high volume of creative resources** in collaboration with community

Other Tips

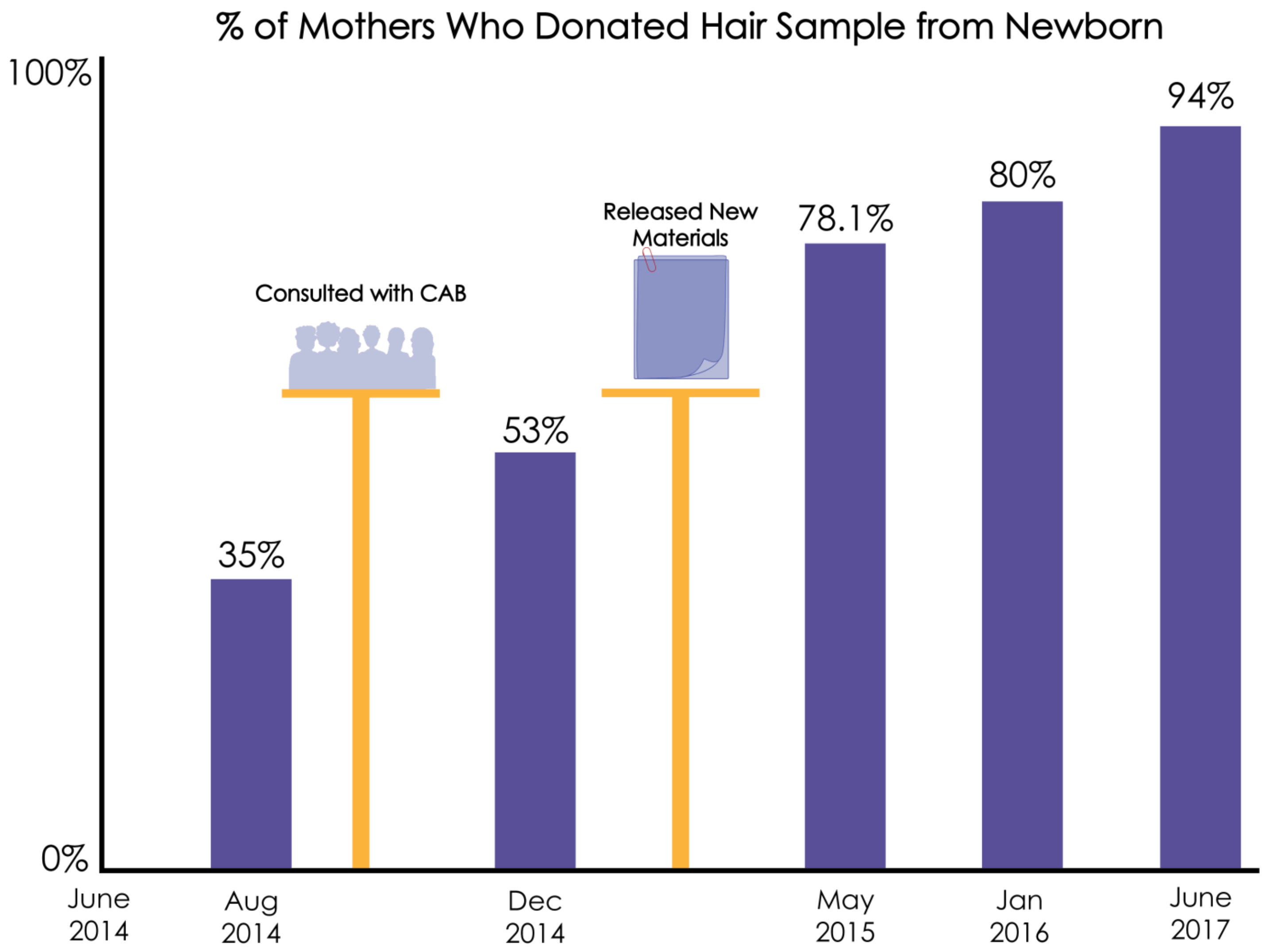
- **Build CE into IRB protocol**
- **Options for financial compensation**
  - Stipend, gift card, ClinCard
  - Consider those without SSN
- **Recruitment**
  - Utilize study structure; word-of-mouth can be best for stigmatized conditions; ensure diversity (including in advocacy & lived experience)
- Language accessibility – translation services can be affordable
- Evaluate your programming!
- **Be flexible with timing and communication**
- Choose a mascot!
- **Use fun/silly icebreakers**
- Balance promoting connection with business
- **Where possible, have in-person opportunities**
- Have a buddy system for calls
- **Make them real relationships!**
  - Check in often, when you don't need anything

CASE STUDY of Tier 3: Pediatric HIV/AIDS Cohort Study (PHACS)

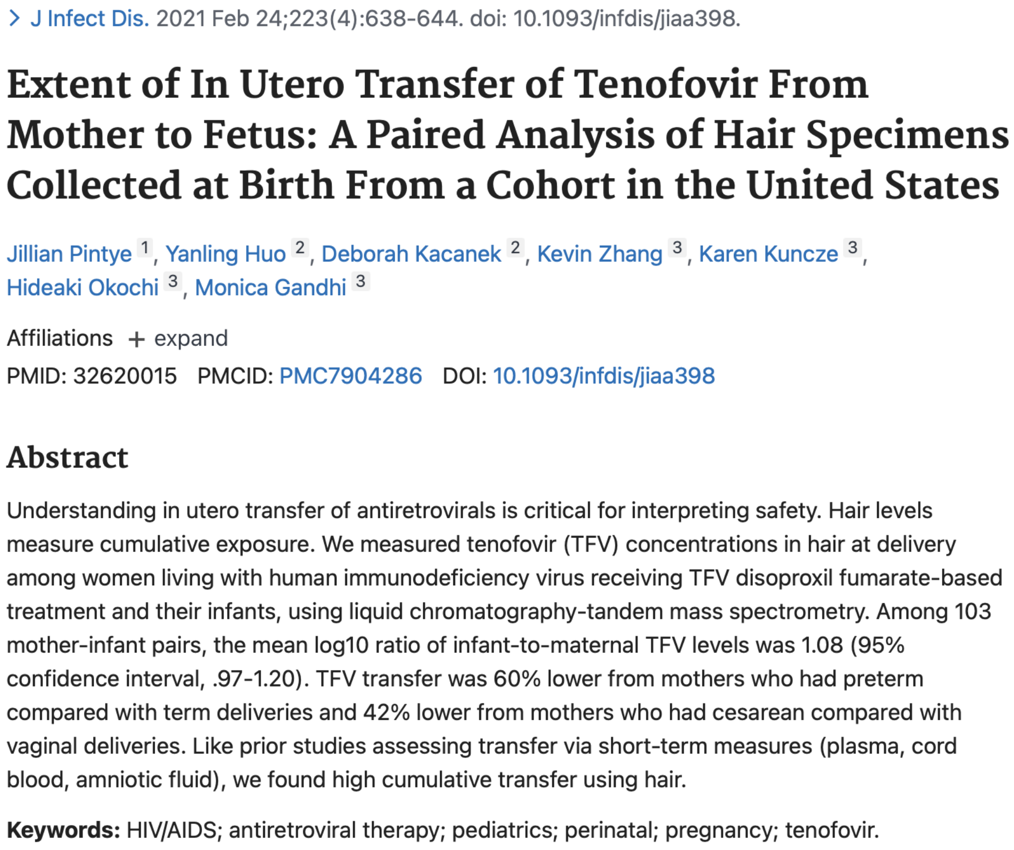
- P01 mechanism, 3 protocols
  - ~6,500 active participants
  - ~ $17 million / year
- **21 clinical sites**, including Puerto Rico
- 14% **speak Spanish** as 1st language
- **Longitudinal research into safety of antiretroviral medications** taken *in utero* or in childhood



Hair Collection Enrollment Over Time



Hair Collection Papers Published



> J Infect Dis. 2021 Feb 24;223(4):638-644. doi: 10.1093/infdis/jiaa398.

Extent of In Utero Transfer of Tenofovir From Mother to Fetus: A Paired Analysis of Hair Specimens Collected at Birth From a Cohort in the United States

Jillian Pintye [1], Yanling Huo [2], Deborah Kacanek [2], Kevin Zhang [3], Karen Kuncze [3], Hideaki Okochi [3], Monica Gandhi [3]

Affiliations + expand

PMID: 32620015 PMCID: PMC7904286 DOI: 10.1093/infdis/jiaa398

Abstract

Understanding in utero transfer of antiretrovirals is critical for interpreting safety. Hair levels measure cumulative exposure. We measured tenofovir (TFV) concentrations in hair at delivery among women living with human immunodeficiency virus receiving TFV disoproxil fumarate-based treatment and their infants, using liquid chromatography-tandem mass spectrometry. Among 103 mother-infant pairs, the mean log10 ratio of infant-to-maternal TFV levels was 1.08 (95% confidence interval, .97-1.20). TFV transfer was 60% lower from mothers who had preterm compared with term deliveries and 42% lower from mothers who had cesarean compared with vaginal deliveries. Like prior studies assessing transfer via short-term measures (plasma, cord blood, amniotic fluid), we found high cumulative transfer using hair.

Keywords: HIV/AIDS; antiretroviral therapy; pediatrics; perinatal; pregnancy; tenofovir.

Observational Study > AIDS. 2021 Feb 2;35(2):267-274.
doi: 10.1097/QAD.0000000000002730.

Detectable HIV RNA in late pregnancy associated with low tenofovir hair levels at time of delivery among women living with HIV in the United States

Jillian Pintye [1], Yanling Huo [2], Deborah Kacanek [2], Kevin Zhang [3], Karen Kuncze [3], Hideaki Okochi [3], Monica Gandhi [3]; Pediatric HIV/AIDS Cohort Study (PHACS)

Affiliations + expand

PMID: 33055571 PMCID: PMC7775322 DOI: 10.1097/QAD.0000000000002730

Abstract

Objective: We evaluated peripartum tenofovir (TFV) exposure via hair measures among women living with HIV in the United States.

Design: Observational cohort study.

Methods: Hair samples were collected at or shortly after childbirth among mothers enrolled in the Surveillance Monitoring for Antiretroviral Therapy Toxicities Study of the Pediatric HIV/AIDS Cohort Study between 6/2014 and 7/2016. Among mothers receiving TFV disoproxil fumarate (TDF)-based regimens during pregnancy, TFV hair concentrations were analyzed using liquid chromatography/tandem mass spectrometry. Weight-normalized TFV concentrations were log10 transformed. Multivariable linear regression assessed correlates of TFV concentrations.

Results: Overall, 121 mothers on TDF-based antiretroviral therapy during pregnancy had hair specimens tested for TFV concentrations and were included in the analysis. Median age at delivery was 31 years [interquartile range (IQR) 26-36]; 71% self-identified as non-Hispanic black, and 10% had unsuppressed viral loads in late pregnancy (HIV RNA ≥ 400 copies/ml). Median time from birth

Additional Examples

Tooth Collection

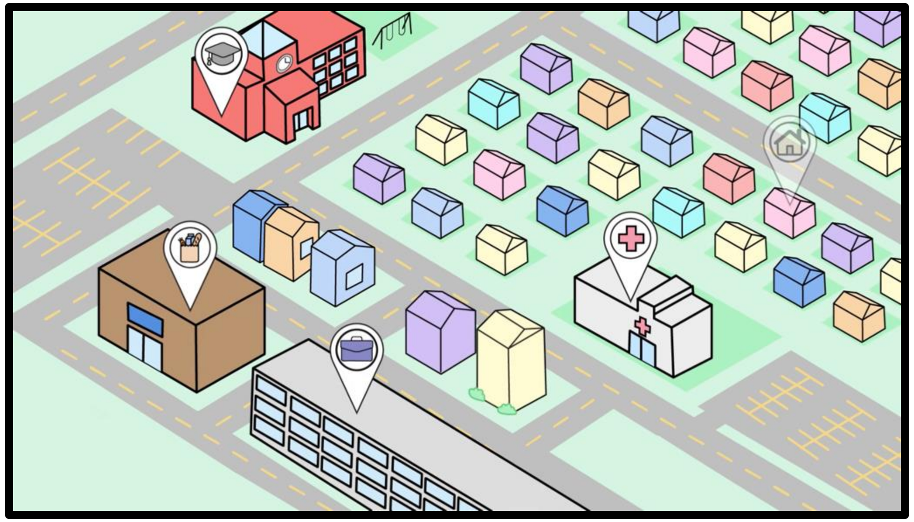
Tooth fairy vs El Ratoncito

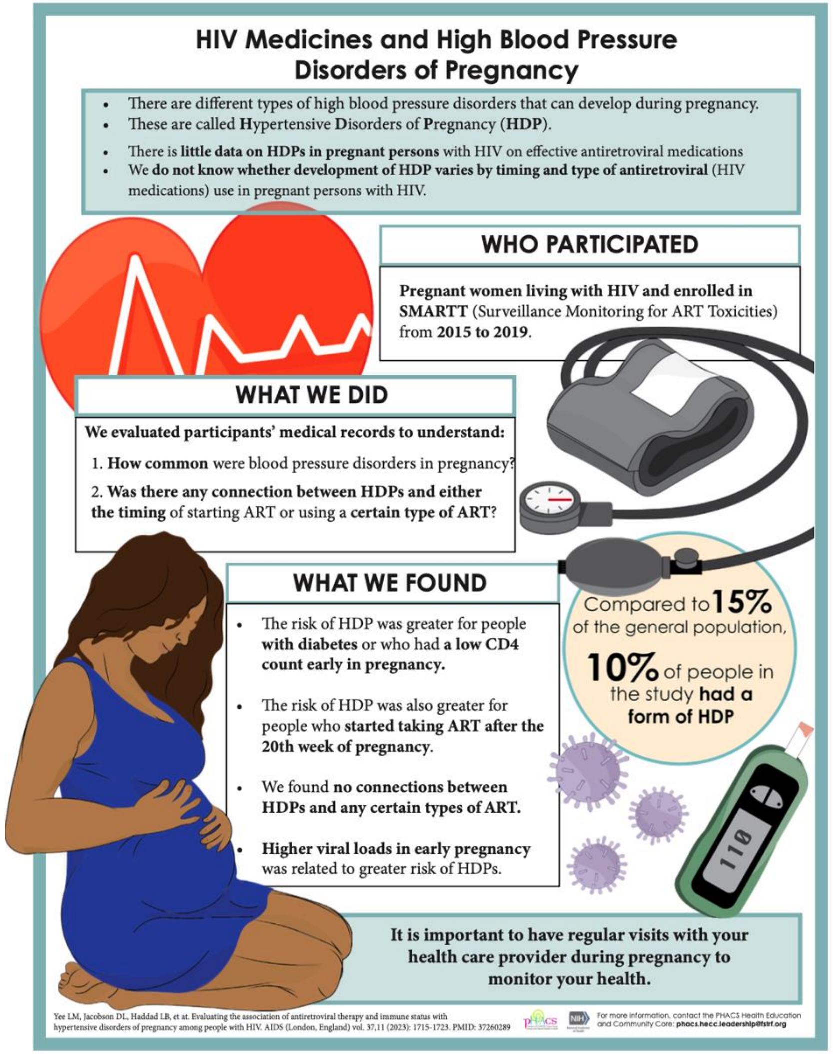
Disclosure Comics

3XHUWR 5LFDQ PRPV·

the image on left

Additional Creative Examples





HIV Medicines and High Blood Pressure Disorders of Pregnancy

- There are different types of high blood pressure disorders that can develop during pregnancy.
- These are called **H**ypertensive **D**isorders of **P**regnancy (**HDP**).
- There is **little data on HDPs in pregnant persons** with HIV on effective antiretroviral medications
- We **do not know whether development of HDP varies by timing and type of antiretroviral** (HIV medications) use in pregnant persons with HIV.

WHO PARTICIPATED

Pregnant women living with HIV and enrolled in SMARTT (Surveillance Monitoring for ART Toxicities) from **2015 to 2019**.

WHAT WE DID

We evaluated participants' medical records to understand:

1. **How common** were blood pressure disorders in pregnancy?
2. **Was there any connection between HDPs and either the timing** of starting ART or using a **certain type of ART**?

WHAT WE FOUND

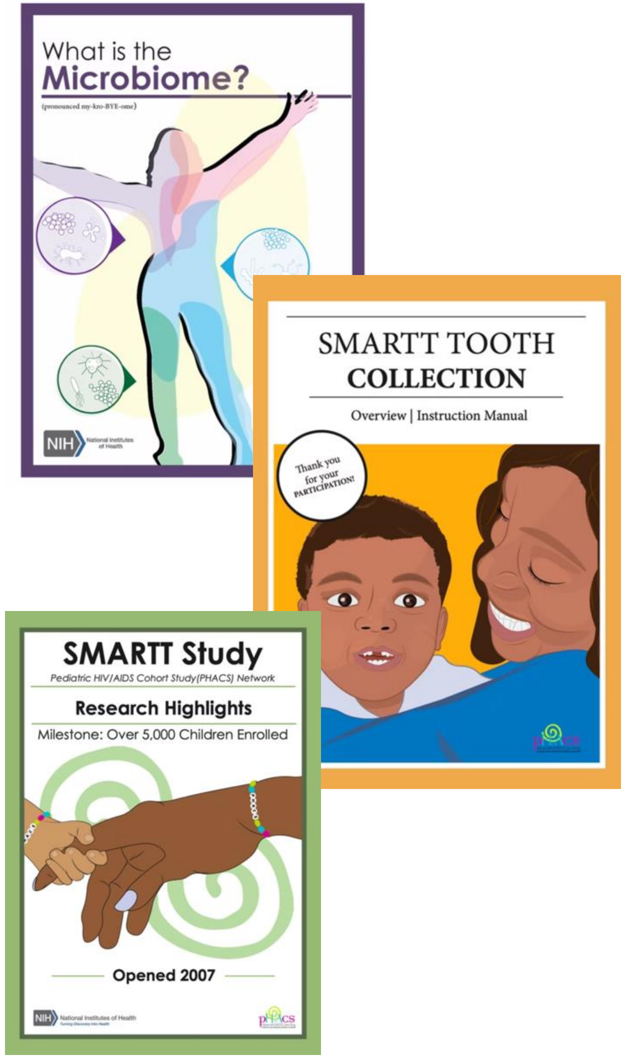
- The risk of HDP was greater for people **with diabetes** or who had **a low CD4 count early in pregnancy.**
- The risk of HDP was also greater for people who **started taking ART after the 20th week of pregnancy.**
- We found **no connections between HDPs and any certain types of ART.**
- **Higher viral loads in early pregnancy** was related to greater risk of HDPs.

Compared to **15%** of the general population, **10%** of people in the study **had a form of HDP**

It is important to have regular visits with your health care provider during pregnancy to monitor your health.

Yee LM, Jacobson DL, Haddad LB, et at. Evaluating the association of antiretroviral therapy and immune status with hypertensive disorders of pregnancy among people with HIV. AIDS (London, England) vol. 37,11 (2023): 1715-1723. PMID: 37260289

For more information, contact the PHACS Health Education and Community Core: **phacs.hecc.leadership@fstrf.org**



What is the
Microbiome?
(pronounced my-kro-BYE-ome)

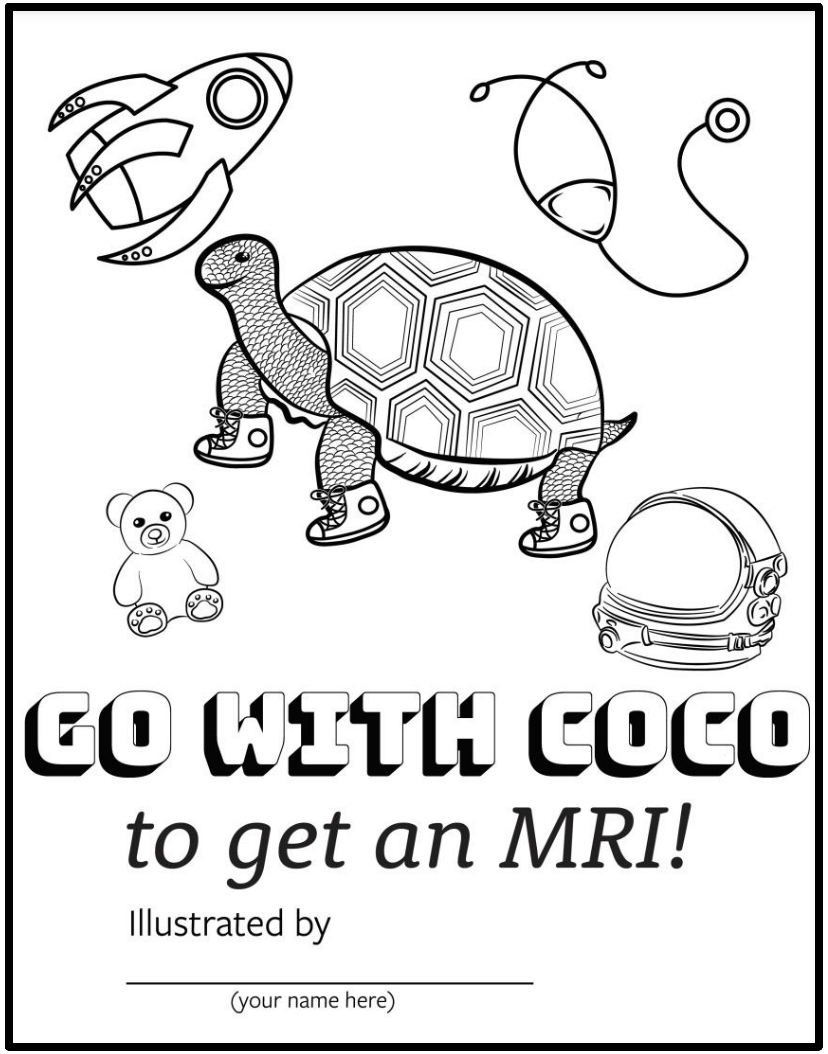
SMARTT TOOTH COLLECTION
Overview | Instruction Manual
Thank you for your PARTICIPATION!

SMARTT Study
Pediatric HIV/AIDS Cohort Study (PHACS) Network
Research Highlights
Milestone: Over 5,000 Children Enrolled
Opened 2007

Additional Creative Examples

HOPE™

TERBO BRAIN STUDY™



GO WITH COCO

to get an MRI!

Illustrated by

____

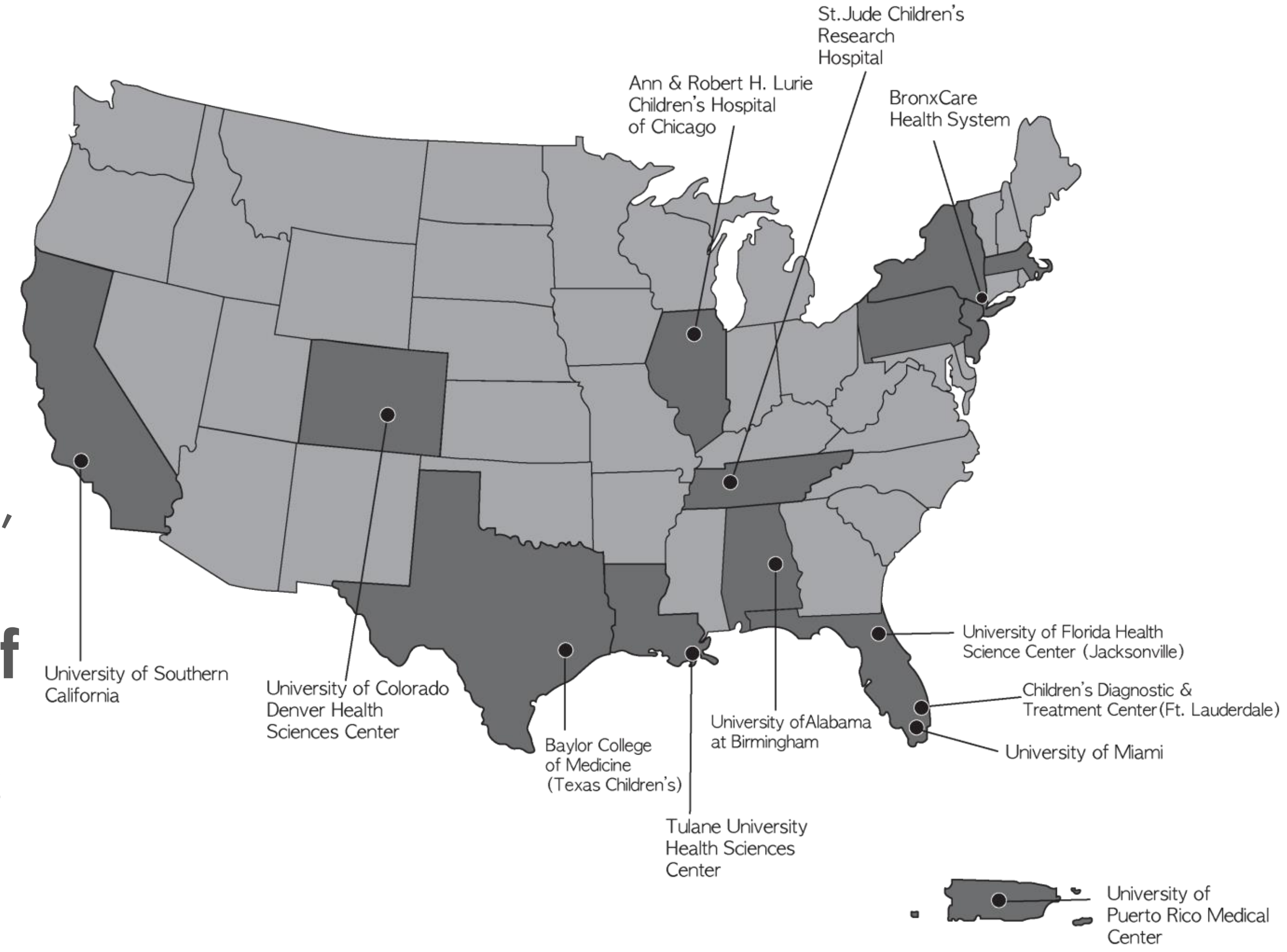
(your name here)

Proud PUG

Proud CAB Member

CASE STUDY of Tier 2: Health Outcomes around Pregnancy and Exposure to HIV/ARVs (HOPE)

- **R01 mechanism**
  - ‡Utilizes PHACS infrastructure
  - ‡$3 million / year, 1 protocol
  - ‡Goal: 1,620 participants
- **14 clinical sites**, including Puerto Rico
- 14% speak Spanish as 1st lang, other languages represented
- **Longitudinal study of health of women** living with HIV over reproductive life course (ages 18-45)

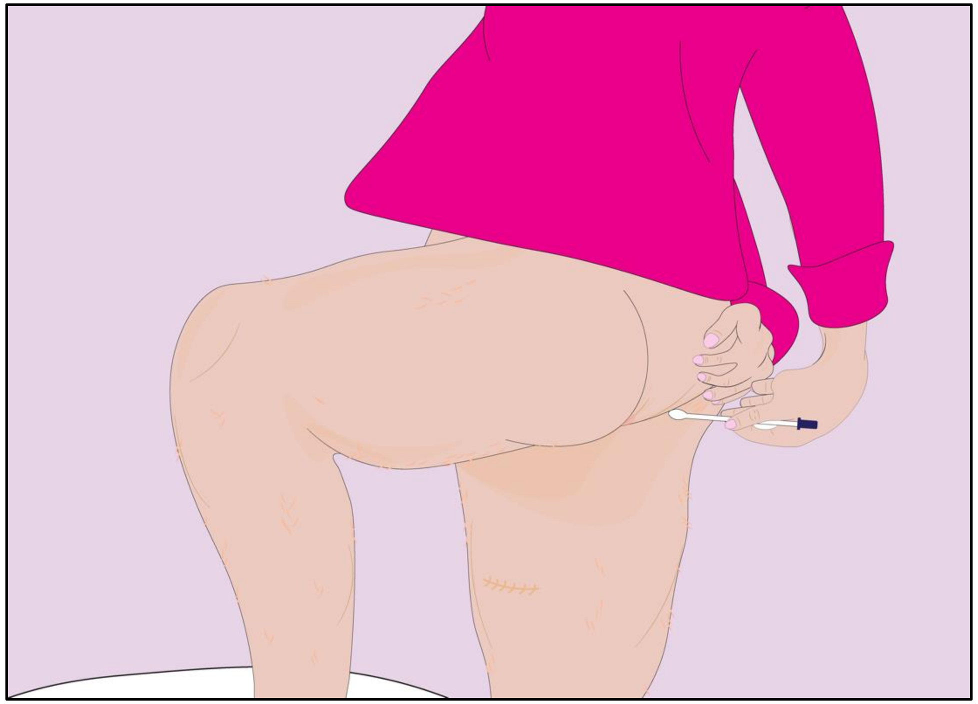


- **3 part-time community liaisons**
    - ~ 5 hours per month
- **Single, unified CAB** with up to 17 members
    - English only
- **5 Community TF** members
    - $30/hour, monthly honorarium
- 5-10% effort of HECC Director
- 5-10% effort of Creative Project Manager

Examples from HOPE

Anal/Vaginal Swabs

- Body-inclusive images to aid in collection



Examples from HOPE

Wearable Device Study

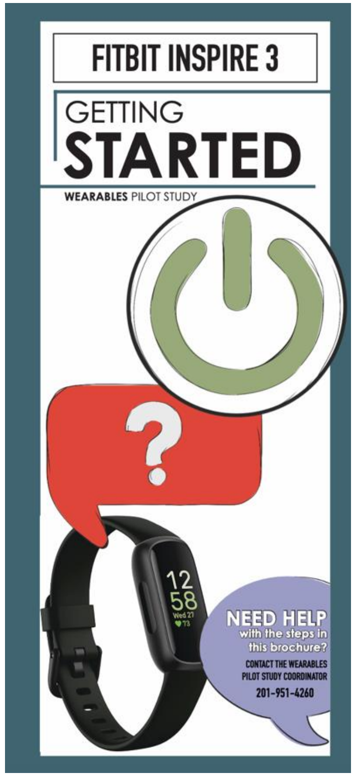
- CAB gave extensive input on initial design of study and on materials
  - Addressed multiple identified barriers to study completion prior to launching
- Goal was to enroll 30 women in **6 months**
- Enrolled 30 women in **2 months**

FITBIT INSPIRE 3

USER
GUIDE

WEARABLES PILOT STUDY

NEED HELP
with the steps in this brochure?
CONTACT THE WEARABLES PILOT STUDY COORDINATOR
201-951-4260



FITBIT INSPIRE 3

GETTING
STARTED

WEARABLES PILOT STUDY

NEED HELP
with the steps in this brochure?
CONTACT THE WEARABLES PILOT STUDY COORDINATOR
201-951-4260

FITBIT INSPIRE 3

FAQs
& TROUBLESHOOTING

NEED HELP
with the steps in this brochure?
CONTACT THE WEARABLES PILOT STUDY COORDINATOR
201-951-4260

Impact of CE on participants

Out of 21 respondents from 2 cohorts (2021-2023 and 2023-2025):

- 18 (**85%**) felt they gained more knowledge about the research process
- 20 (**95%**) felt they gained more knowledge about PHACS/HOPE protocols
- 21 (**100%**) IHOW VWURQJHU LQ ³EHLQJ DQ DGYRFDWH IRU RWKHUV LQ
- 21 (**100%)** IHOW VWURQJHU LQ ³EHLQJ DQ DGYRFDWH IRU P\ RZQ KHD
- 21 (**100%** IHOW VWURQJHU LQ ³EHLQJ DQ DGYRFDWH IRU P\VHOI LQ J
- 19 (**90%** IHOW VWURQJHU LQ ³IHHOLQJ HPSRZHUHG DV D VWXG\ SDU
- 21 (**100%** IHOW VWURQJHU LQ ³IHHOLQJ UH́VLOLHQW ZKHQ , HQFRXQ
- 19 (**90%** IHOW VWURQJHU ´LQ ³VRFLDO VXSSRUW
- **20 (95%) rated experience of Task Force participation as “very positive,”** including those who left TF before the full 2-year term had ended. (1 neutral)

Even though it was remote, **I felt my opinion was heard and valued.** I like how thoughtful the team was in seeking feedback.

³, UHDOO\ HQMR\HG **having a voice in subjects that affect those that are like myself or within the community of HIV**. I enjoy being able to give a different perspective other than just a clinical perspective. I also cherished having the **community feel** ´

³%HLQJ D SDUW RI WK community has impacted my life in a good way. I am more thoughtful about my health. I am able to work with world-class professionals, and most LPSRUWDQWO\, « **contribute to medical research that will have impact on lives and generations to come** ´

Being a part of PHACS has definitely **helped me shed some of the stigma on myself that I didn’t know I was holding**. I was able to be open with my partner about issues in the HIV community and have been able WR FRQQHFW RQ D GHHSHU OHYHO ´

One of the biggest things that I would like to tell is **seeing our projects come full circle**. And being able to explain to our local cab when a new study is out the ins and outs of that particular study.

³$OO RI WKH participants were **part of the studies that we were surveyed on**. I believe that **helped our responses be more personal** ´

³, ORYH EHLQJ D SDUW RI **real change** ´

³%HIRUH MRLQLQJ WKH Task Force, I **used to be bashful about HIV** and not be open to talking about it. **Now I share all of my knowledge** with my partner and mom and am open about sharing my RSLQLRQV ´

³:KDW , ORYH DERXW WKH &7) LV WKH sense of **knowing I am heard**. It's like-minded people exchanging thoughts on matters WKDW WKH\ DUH DIIHFWHG E\ ´

³,W KDV DOORZHG PH WR understand studies that I participate in better. They make sense and **I don't see a bunch of scientists judging my lifestyle choices, but looking for ways to understand me** ´

“I will never forget my second call. I **disagreed with something that was said** and I played the devils advocate. My opinion was well received and **opened up others’ minds to my perspective.**”

“One of the most importan things that I love about being apart of the Community Task Force is that I know that **not only my voice is being heard , but my local CAB members are as well.”**

Choosing the right tier for your research

- o **Consider possible budget and funding sources**
  - ‡% staff time, grant funding (either standalone or embedded), institutional fundraising office
  - ‡Can incentives be donated (i.e., museum, movie theater, zoo, bowling alley)?
- o **Assess current staff skills and expertise**
  - ‡7KLQN RXWVLGH WKH ER[ZKR·V D SHRSOH SH
    a good game show host, who has tech skills, who is an artist?
- o **Assess and utilize institutional support**
  - ‡Admin support? Media or communications office? Professional development trainings?

Choosing the right tier for your research

- **Study size, # participants, participant demographics**
  - Tier 1 could be appropriate for smaller study; Tier 3 for large study
  - Do participants have kids? Are they young adults? Children?
  - Can you recruit via clinics, via email, etc. (IRB considerations)
- **Is your study local or does it cover a large geographic area?**
  - This will determine in-person vs virtual meetings
- **How to scale up over time**
  - :ULWH FRPPXQLW\ HQJDJHPHQW LQWR QHZ UR
  - Collect evaluation data where possible to make your case to funders
  - Add components into new grants or funding opportunities

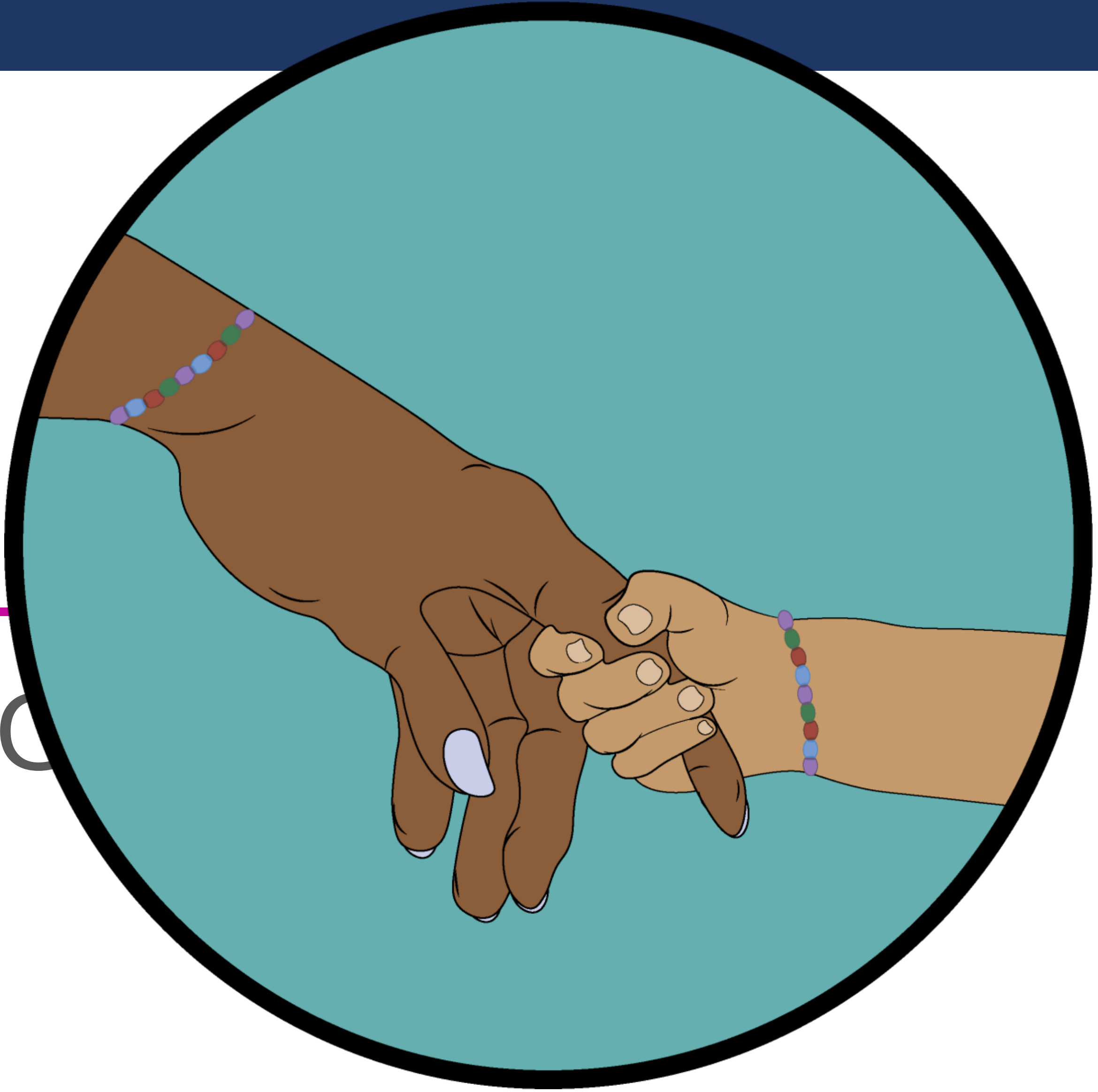
Overcoming challenges
in community engagement

- **Addressing skepticism** from researchers and communities
  - ‡Appeal to shared values, to value-add in quantitative terms
- **Limitations** in disbursing payments
  - ‡Institutional limitations of disbursing stipends; consistency is key
- Ensure **sustainability of engagement** efforts
  - ‡Consistent staffing, trust, document processes, in-person meetings
- **Tips for maintaining trust and transparency**
  - ‡Create real relationships, not transactional; respect confidentiality
  - ‡Follow through on promises, including incentives/payments
  - ‡Communicate clearly, esp with budget issues; best to tell a hard truth than inadvertently undermine trust with sugarcoating

FURTHER RESOURCES

www.phacsstudy.org
www.ourprojectpositive.com

´'RQ·W IRUJH
human LQ WKH



Past and Current PHACS US Clinical Sites

- Ann Robert Lurie Children's Hospital of Chicago
- Baylor College of Medicine
- BronxCare Health System
- Children's Diagnostic & Treatment Center
- Children's Hospital Boston
- Children's Hospital of Philadelphia
- Harvard T.H. Chan School of Public Health
- Jacobi Medical Center
- New York University School of Medicine
- St Christopher's Hospital for Children
- St. Jude Children's Research Hospital
- San Juan Hospital/Department of Pediatrics
- SUNY Downstate Medical Center
- SUNY Stony Brook
- Tulane University Health Sciences Center
- University of Alabama, Birmingham
- University of California, San Diego
- University of Colorado Health Sciences Center
- University of Florida/Jacksonville
- University of Illinois, Chicago
- University of Maryland, Baltimore
- Rutgers- New Jersey Medical School
- University of Miami
- University of Southern California
- University of Puerto Rico Medical Center

PHACS is funded by:

National Institutes of Health

Under cooperative agreements HD052102 (Harvard T.H. Chan School of Public Health), HD052104 (Tulane University School of Medicine), and P01HD103133 (Harvard T.H. Chan School of Public Health for the Pediatric HIV/AIDS Cohort Study (PHACS) 2020).

We thank the study participants, clinical sites, PHACS Community Advisory Board, Frontier Science, and Westat.

REACH OUT

Claire Berman:
www.ClaireABerman.com
claireberman@gmail.com

Amanda Flores:
amanda.caitlin.flores@gmail.com
Website coming soon!

Kimbrae S:
kimbraels@gmail.com