

# “It’s like you need the participants, but you’re not willing to invest in them”: Exploring stakeholders’ perceptions of incentives in the U.S. HIV research enterprise

Karah Y. Greene,<sup>1</sup> Brandon Brown,<sup>2</sup> Karine Dubé,<sup>3</sup> Andrea N. Polonijo<sup>4</sup>, Jerome T. Galea<sup>1</sup>

1. University of South Florida School of Social Work, 2. University of California, Riverside, School of Medicine

3. University of California, San Diego, School of Medicine, 4. University of California, Merced Department of Sociology and the Health Sciences Research Institute

## BACKGROUND

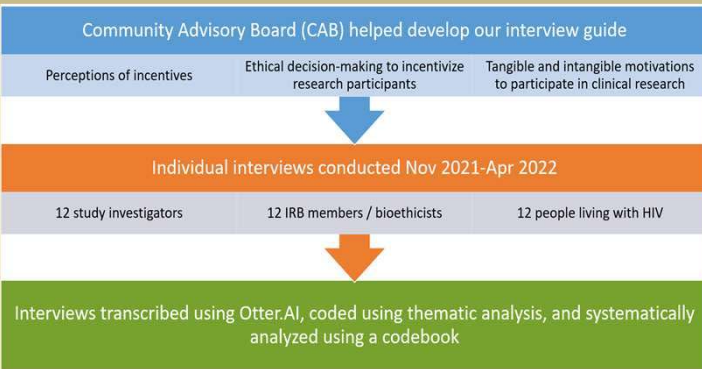
### Types of Research Payments

REIMBURSEMENT	Re-payment for out-of-pocket expenses personally incurred as part of research participation
COMPENSATION	Paid for time and undertaking burdens of research
INCENTIVES	Offered to improve recruitment and participation rates

- Little understanding of how payment amounts are determined for research participation
- Unclear how payment influences research participant decision-making

**Aim:** To assess the perceptions of research payment and incentives among different HIV research stakeholders

## METHODS



## RESULTS

- Age range: 24-85 years
- 61% female
- 42% Hispanic or non-White
- Range of reported average payment amount per research project: \$0-\$2500
- Most (n=28; 78%) considered payment to be a benefit of research participation.

### Shared Perspectives

- Participants should not incur out-of-pocket expenses.
- Post-study access to efficacious intervention= incentive
- Decisionmakers should consider the background of the target population.

Perspectives from people living with HIV were a key component of our study.

### People Living with HIV

"How do you feel about the community? If those incentives are low, you will suffer in recruitment and retention. People will recognize and they will think that you want us to do a lot, yet you don't want to respect us."

"You have to first build a trusting relationship with your population. Researchers have to be very aware when going out and asking these qualitative questions..."

"I think stigma has killed more people than the disease. So just letting us share with you some of our obstacles, some of our triumphs and tragedies...that could help."

## CONCLUSION & NEXT STEPS

- There is a disconnect between stakeholder groups and their views on research incentives.
- Interview results informed the next phase of our study, which was to develop HIV-related hypothetical study scenarios (vignettes) and present them to the different stakeholders for their decision-making on what is an appropriate incentive amount.

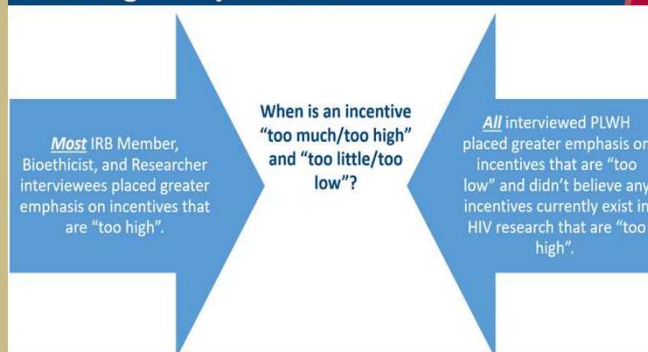
**We aim to use our findings to develop a framework that integrates the varying stakeholder perspectives and can guide decision-making for ethical research incentives in future studies.**

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### Differing Perspectives



Comments & Questions?  
Email: karahgreene@usf.edu