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**“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**

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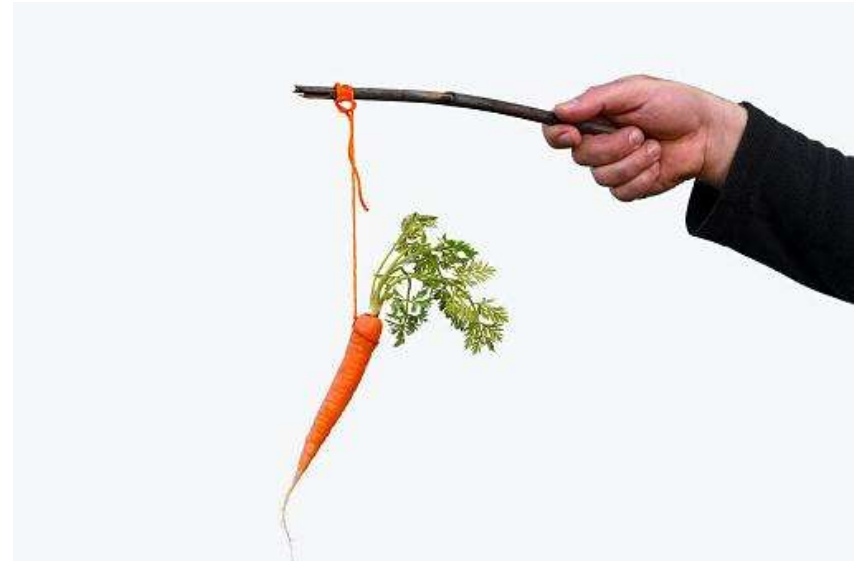
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Types of Research Payments

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

Background & Study Aim



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

Methods

Community Advisory Board (CAB) helped develop our interview guide

Perceptions of incentives

Ethical decision-making to incentivize research participants

Tangible and intangible motivations to participate in clinical research



Individual interviews conducted Nov 2021-Apr 2022

12 study investigators

12 IRB members / bioethicists

12 people living with HIV



Interviews transcribed using Otter.AI, coded using thematic analysis, and systematically analyzed using a codebook

Sample (N=36)

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.

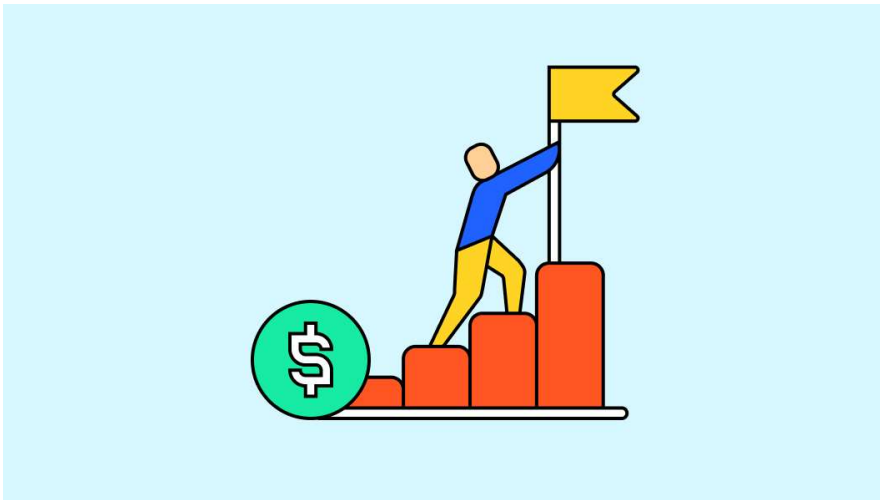
People Living with HIV

"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."

IRBs and Ethical Implications



Undue inducement: offering an excessive or inappropriate incentive in order to obtain compliance

Researchers



budget constraints



varying perceptions of motivations to participate in research

“I feel like what I'm bringing is me, and that's valuable, the compensation is in the experience.”
– PLWH

Differing Perspectives

Most IRB Member, Bioethicist, and Researcher interviewees placed greater emphasis on incentives that are “too high”.

When is an incentive “too much/too high” and “too little/too low”?

All interviewed PLWH placed greater emphasis on incentives that are “too low” and didn’t believe any incentives currently exist in HIV research that are “too high”.

Shared Perspectives



Participants should not incur out-of-pocket expenses to participate (should be reimbursed).



Study population should be a factor when determining ethical incentives.



Access to efficacious interventions post-study is an incentive.

Limitations

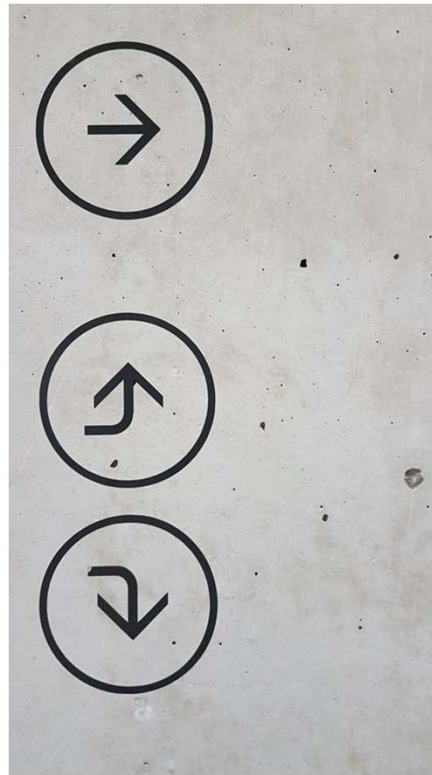


Sample was limited to 36 participants
from three stakeholder groups



Recruitment conducted primarily
through personal connections

Conclusion & Next Steps



Questions?

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Thank You