

# Ethical Incentives and Stakeholder Concerns

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Evaluating the Impact of  
**INCENTIVE\$**  
on Clinical Trial Participation

# RESEARCH TEAM



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*Empirical Research on Ethical Issues in Clinical Research and Research with  
Special Populations*



## Determining Ethical Incentives in Biomedical HIV Research: Insights from Researchers, Regulators, and People Living with HIV

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### Abstract

Incentives are crucial for recruiting and retaining participants in research studies, yet researchers and regulators often struggle to determine appropriate incentives due to ethical concerns and a lack of clear guidelines. We conducted interviews and focus groups with three stakeholder groups—biomedical HIV researchers (n = 12), institutional review board (IRB) members (n = 12), and people living with HIV (PLWH) (n = 69)—to explore their perspectives on incentives and ethical decision-making in biomedical HIV research. Our findings revealed disparities in perspectives; researchers and IRB members were most concerned about offering high incentives, while PLWH were most concerned about incentives being too low. Consensus highlighted the need for diverse incentive options, transparency, standardized guidelines, and community engagement to address both ethical and practical challenges.

### Keywords

HIV, people living with HIV, incentives, ethical payments, compensation, reimbursement, research participation

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# OUTLINE



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BACKGROUND

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STUDY AIMS

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METHODS

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FINDINGS

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IMPLICATIONS FOR RESEARCH, POLICY, & PRACTICE

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FUTURE RESEARCH

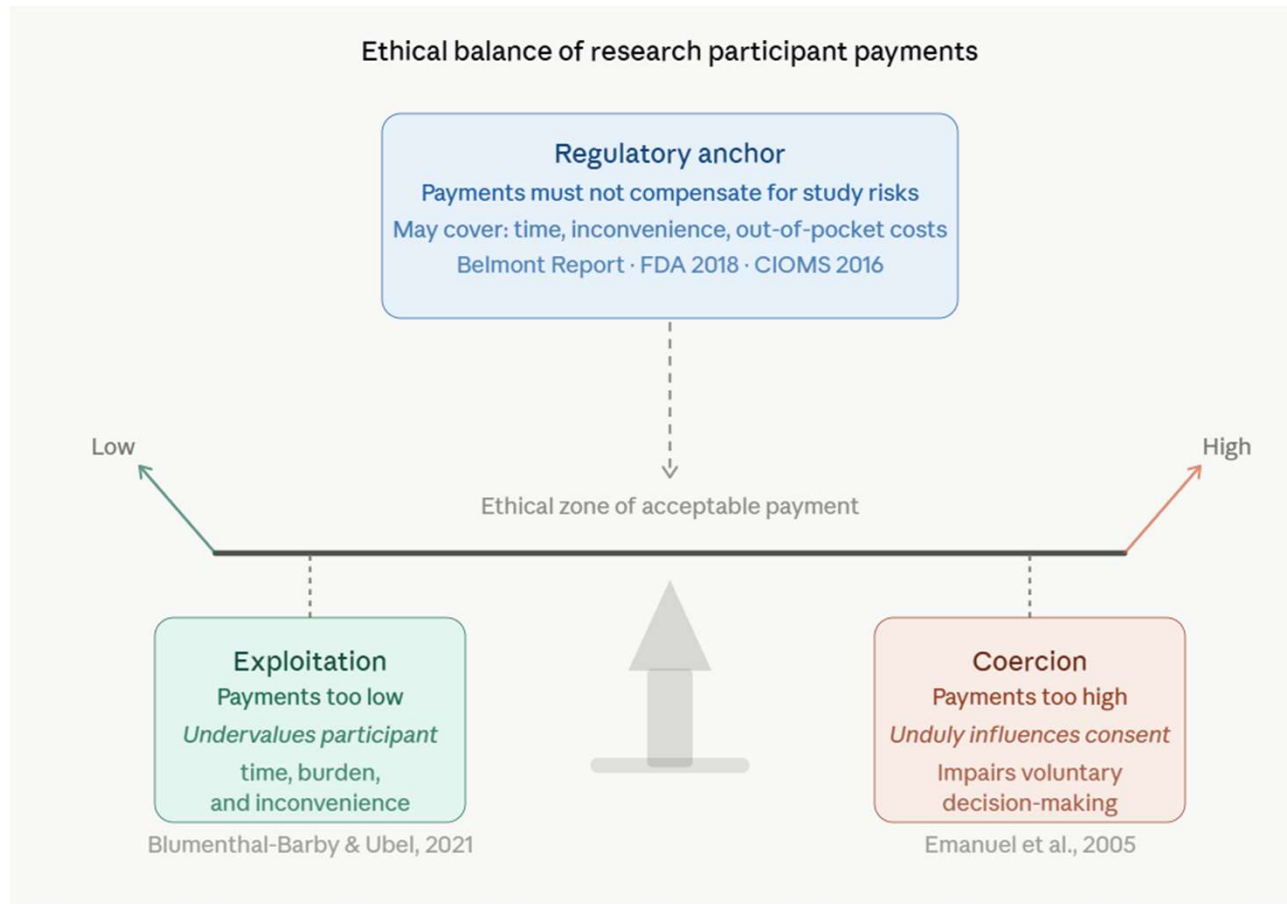
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QUESTIONS & COMMENTS

## **Incentives:**

payments or benefits (e.g., cash, gift cards, services) offered to research participants to encourage participation and improve recruitment and retention, beyond reimbursement for expenses or compensation for time and inconvenience

# BACKGROUND



Source:  
Claude AI-generated figure

## What is missing?

- Standardized guidance for determining appropriate types or amounts
- Systematic reporting of incentive data
- Incentive decisions often rely on **subjective assessments** of risks, burdens, and benefits influenced by institutional norms, precedent, regulations, and advice from other investigators + practical factors like study procedures, time commitment, population, and budget
  - substantial variability in incentive practices, even within the same institutions



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## Evaluating the Impact of Incentives on Clinical Trial Participation: Protocol for a Mixed Methods, Community-Engaged Study

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**DE**

[What is this?](#)

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- [Abstract](#)
- [Introduction](#)
- [Methods](#)
- [Results](#)
- [Discussion](#)
- [References](#)
- [Abbreviations](#)
- [Copyright](#)

### Abstract

#### Background:

Monetary incentives in research are frequently used to support participant recruitment and retention. However, there are scant empirical data regarding how researchers decide upon the type and amount of incentives offered. Likewise, there is little guidance to assist study investigators and institutional review boards (IRBs) in their decision-making on incentives. Monetary incentives, in addition to other factors such as the risk of harm or other intangible benefits, guide individuals' decisions to enroll in research studies. These factors emphasize the need for evidence-informed guidance for study investigators and IRBs when determining the type and amount of incentives to provide to research participants.

#### Objective:

The specific aims of our research project are to (1) characterize key stakeholders' views on and assessments of incentives in biomedical HIV research; (2) reach consensus among stakeholders on the factors that are considered when choosing research incentives, including consensus on the relative importance of such factors; and (3) pilot-test the use of the guidance developed via aims 1 and 2 by presenting stakeholders with vignettes of hypothetical research studies for which they will choose corresponding incentive types.

Health Disparities

HIV and Aging

HIV and Substance Use

HIV Genetic Sequencing

Hot Topics in HIV Research

**Attitudes Toward Payment for Research Participation: Results of a U.S. Survey of People Living with HIV** [↗](#)

May 4, 2022. Hosted by HANC. Presenter: Andrea Polonijo

**A Conversation with Black and African American Researchers** [↗](#)

November 4, 2021. Hosted by the New Investigators Working Group. Presenters: Greg Millett, LaRon Nelson, Darren Whitfield. Moderators: Christopher Hucks-Ortiz and Typhanye Dyer

**Cure Research: What is it and what do you need to know?** [↗](#)

August 22, 2023. Hosted by Community Partners. Presenters: Dr. Marina Caskey, Jan Kosmyna, Katrina Millard

**Ecos de IAS 2025 y Nuevos Avances en el Campo de la Cura** [↗](#)

September 23, 2025. Hosted by Community Partners. Presenters: Natalia Laufer and Gabriela Turk

**Ethical Considerations on Standard of Care and Post-Trial Access** [↗](#)

April 6, 2016. Hosted by Community Partners. Presenters: Liza Dawson and Sam Garner.

# STUDY AIMS

We conducted qualitative interviews and focus groups with **people living with HIV (PLWH), HIV researchers, and IRB members/bioethicists** to:

- (1) compare their views on incentives
- (2) explore ethical considerations that shape incentive decisions in biomedical HIV research



## METHODS: PARTICIPANT RECRUITMENT

- 12-member community advisory board (CAB)



- Data collection period: November 2021 - May 2022
- Sampling strategy: purposive

Age  
18+

Spoke  
English

Had a phone  
or internet  
access

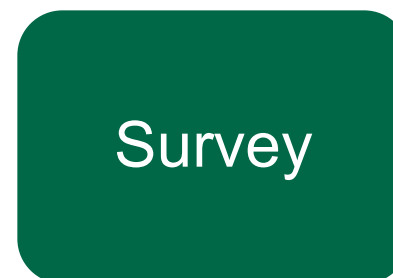
PLWH, IRB  
member/Bioethicist,  
HIV researcher

# METHODS: DATA COLLECTION

**Table 1.** IRB-Approved Interview and Focus Group Questions.

Question	Researchers & IRB Members	Persons Living with HIV
<i>Perceptions of incentives</i>		
Have you ever been involved <sup>a</sup> in a research project with an incentive? Probes: What do you recall about the incentive provided? What was it?	X	X
How do you feel about research incentives? Probes: Are they good, are they bad, why?	X	X
What are your thoughts about the amount of financial incentives offered to participate in research? Probes: When would an incentive be "too high/too much" or "too low/too little"? What impact do you see for incentives that are "too high/too much" or "too low/too little"?	X	X
Are you more concerned about incentive payments that are too high or too low? Why?	X	
How does the offer of an incentive affect your decision to participate in research?		X
If a research study offers you an incentive to take part, how would that affect your willingness to be a study participant? Probes: What is too much? What is too little?		X
<i>Ethical decision-making regarding incentivizing research participants</i>		
How should decision makers decide on what incentive amounts are appropriate? Probes: Personal knowledge, history, database, possible study related harm	X	X
What factors do you think people (researchers, ethics boards) should consider when making decisions about the type and amount of incentives to offer a study participant? Probes: Location, population, risks, budget, advice	X	X
Which form of incentive do you feel most confident providing to study participants? Probes: Cash, gift card, gift, other; why?	X	
Which form of incentive would you be most interested in receiving to participate in a research study? Probes: Cash, gift card, gift, other; why?		X

Note: <sup>a</sup>"Involved" was replaced with "participated" when interviewing people living with HIV.



- Consent
- Demographic information
- Initial perceptions of incentives

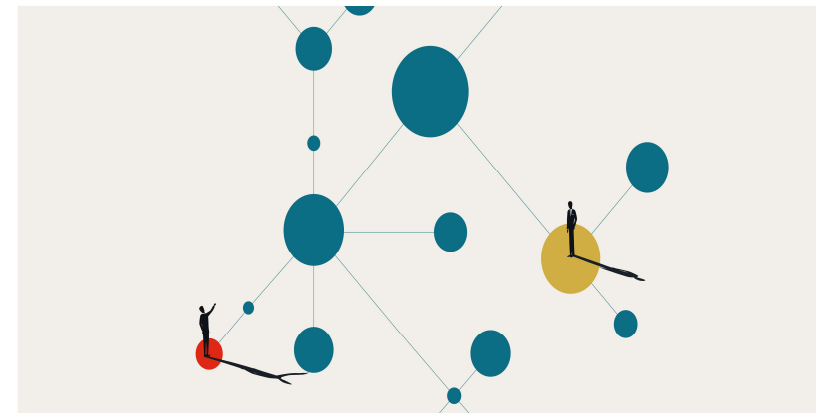


- Via Zoom
- 15-60 min interview or 90-min FG

# METHODS: DATA ANALYSIS

Framework analysis approach ([Ritchie & Lewis, 2003](#))

- 1) Reviewed de-identified transcripts to propose preliminary codes
- 2) Compiled de-identified responses into a master Microsoft Excel spreadsheet and systematically coded text segments by question block
- 3) Synthesized the coded data into narrative summaries
- 4) Independent review of final codes, categories, themes, and summaries to ensure analytic coherence and development of an illustrative coding tree
- 5) All authors reviewed the final narrative summaries and contributed to the development of ethical considerations + integration of CAB feedback



# FINDINGS

**Table 2.** Demographic Characteristics of Participants by Stakeholder Group (N = 93).

Variable	Persons Living with HIV (n = 69)	Researchers & IRB Members (n = 24)
Age, mean; SD (range)	56.1; 10.10 (23–71)	52.0; 17.02 (24–85)
<i>Sex at Birth, n (%)</i>		
Female	23 (33.3)	12 (50.0)
Male	46 (66.7)	12 (50.0)
<i>Gender, n (%)</i>		
Woman	22 (31.9)	10 (41.7)
Man	44 (63.8)	13 (54.1)
Other	3 (4.3)	1 (4.2)
<i>Ethnicity, n (%)</i>		
Hispanic/Latinx	14 (20.3)	1 (4.2)
Not Hispanic/Latinx, or unknown	55 (79.7)	23 (95.8)
<i>Race, n (%)</i>		
Black/African American	28 (40.6)	1 (4.2)
White	30 (43.5)	18 (75.0)
Other/multiple races-ethnicities	11 (15.9)	5 (20.8)
<i>Educational Attainment, n (%)</i>		
High school	6 (8.7)	0 (0)
Some college	27 (39.1)	0 (0)
Undergraduate degree or equivalent	13 (18.8)	3 (12.5)
Master's degree or equivalent	9 (13.0)	2 (8.3)
Doctoral degree or equivalent	14 (20.3)	19 (79.2)

## Diverse Incentives Reported, Cash Incentives and Choice Preferred

Theme	Category	Code(s)	Illustrative Quote
<b>Theme 1: Diverse Incentives Reported, Cash Incentives and Choice Preferred</b>	Variation in Incentive Amounts and Forms	Incentive scaled to study burden and risk	“Typically, the monetary incentives were tied into the amount of risk and discomfort pain that the individual would be going through.” (IRB member, non-Hispanic White man)
		Monetary incentive forms	“...back in the day they used cash and now they use gift cards.” (PLWH, White woman)
		Non-monetary incentive forms	“The incentive attached was... access to medicine, and the healthcare associated with that.” (PLWH, non-Hispanic White man)
	Preferences for Incentive Type	Cash	“Cash, cash, cash... because I can then turn that into whatever I want it to be... pay a phone bill... if you gave me a gift card, I'm limited” (PLWH, non-Hispanic Black man)
		Gift or debit cards	“Gift cards are the easiest ... cash is a nightmare as far as from a university level and jumping through hoops” (IRB member, non-Hispanic White woman)
	Choice and Flexibility	“Participants should be given a choice.... people [who do] not have a social security number... think through how those individuals could be legally compensated.” (Researcher, non-Hispanic multi-racial man)	

## *Incentives as Recruitment Tools and Expressions of Appreciation*

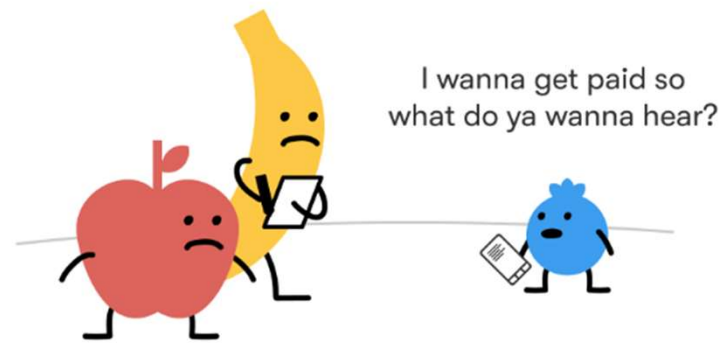
“[Receiving an incentive] makes me feel like they value my participation.... my time is valuable...it makes me feel like I am part of the team, because all of them are getting paid.”

-PLWH, non-Hispanic Black woman

“I really think of it [incentives] as just a respectful way to show appreciation for someone's time and willingness to help us. Because without participants, there would be no research.”

-IRB member, non-Hispanic White woman

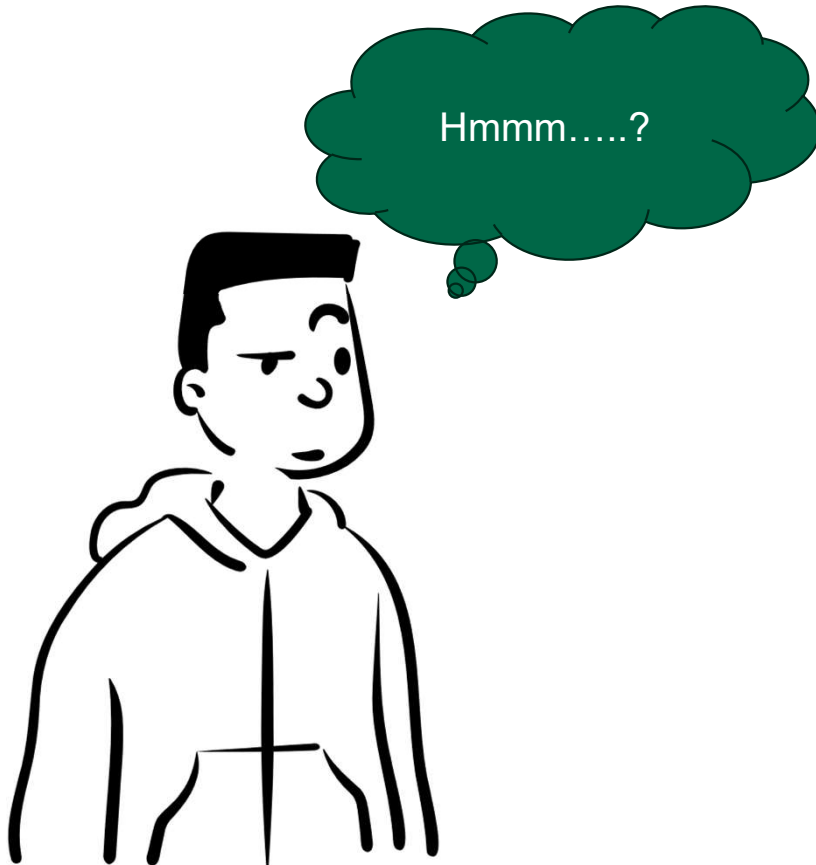
# *Ethical Concerns About High Incentives*



When participants get real

© anAppleandBanana

# *Low Incentives Deter Participation and Undermine Trust*



Time  
commitment

Procedural  
invasiveness

Required  
follow-up /  
study visits



# Population-Specific Factors Should Guide Ethical Incentive Design

<b>Theme 5: Population-specific Factors Should Guide Ethical Incentive Design</b>	Contextual factors shape risk, burdens, and participation	Socioeconomic status	“If these people are maybe more needy, or on fixed incomes on disability... [researchers] should consider paying a little more than if they were targeting people that are more middle class and had higher income annual incomes” (PLWH, non-Hispanic White woman)
		Gender, Race, and Ethnicity	“...if we can offer a little bit more money and be able to recruit more women and underserved participants from racial minorities, or gender minorities, that will be totally worth it to me.” (Researcher, non-Hispanic White woman)
		Geographic location	“People in [City A] have more access to supermarkets and stuff like that. Whereas in [City B], you wouldn't have as much access... you might want to give them a different kind of incentive so that they can get the same benefit.” (PLWH, non-Hispanic White man)
		Disease-specific Context	“...there are two types of AIDS patients...one... has something wrong with them that needs to be treated under a standard of care... the other... all they have is an HIV infection, and they're stable on therapy... A healthy person with AIDS undergoing novel therapies can be subjected to a significantly increased risk relative to the treatment...ethically, you need to be thinking about those two elements and how do you coax that person into the latter.” (Researcher, non-Hispanic White man)

## Collaborate with Community Members to Guide Ethical Incentivization

Theme	Category	Code(s)	Illustrative Quote
<b>Theme 6: Collaborate with Community Members to Guide Ethical Incentivization</b>	Community expertise as central to ethical incentivization	Participant-defined fairness and worth	“To build that trust, and actually get good data, you need to hear ... what [participants] they feel their time, their bodies are worth.” (Researcher, non-Hispanic White nonbinary person)
		Community knowledge as evidence for incentive decisions	“...where the incentive seems high to people on the IRB, we've actually asked study teams to go out and provide a justification for it by talking to members of the community from which they'll be recruiting.” (Researcher, non-Hispanic White man)
	Structures for community input	Consultive structures for community input	“Whether that's through community advisory boards... or even... in-depth interviews... community members should be consulted when those numbers [incentive amounts] are set.” (PLWH, non-Hispanic multi-racial woman)
		Formal employment of community members	“I think it is very important... to have a person living with HIV on staff.” (PLWH, Hispanic Black woman)

# *Enhance Transparency and Standardization in Incentive Decisions*

\$150?  
\$100? ...  
Should it be  
a gift card?



I'll ask my  
colleague about  
incentives. He  
recruited a lot  
of people for  
his study...



## Key Takeaways

94% of PLWH in our study viewed incentives as a benefit of research participation.

Perceptions of ethical incentive amounts differed by stakeholder group.

Study population factors should guide incentive decisions. We need greater transparency and standardization in how incentives are determined.

Involve community members in determining incentive types and amounts.

## Limitations

Incentive amount (\$25 USD) may have attracted or deterred participation depending on prospective participant factors

Evaluative framing of questions

Conducting interviews and focus groups in English via teleconference excluded non-English speakers and those without reliable phone or internet access.

Focus groups may foster groupthink

Formal member checking was not conducted

# **IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE**

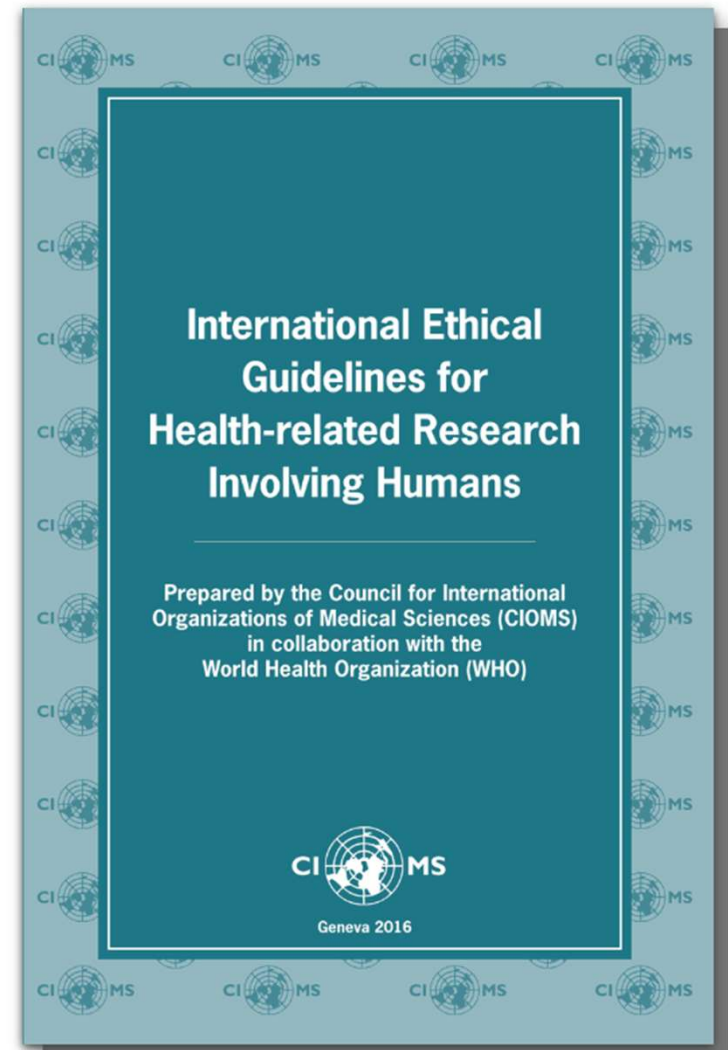
# IMPLICATIONS

**Consider** 1) the specific needs and preferences of the participant group and 2) broader factors that may exclude individuals from participation.

**Facilitate discussions** that incorporate the perspectives of the participant community.

**Include this topic in ethics-focused conference panels** to foster greater understanding and collaboration across stakeholders.

**Refine** CIOMS guidance.



# Future Research



Prioritize the inclusion of the research participant community in discussions about incentives



Explore the dynamics of collaboration among stakeholder groups



Involve other groups: funding agencies, grant writers, budget officers



Explore intangible motivations for research participation



Collect both qualitative and quantitative national data

## Gratitude & Appreciation

- ❖ Considerations Around Study Honoraria (CA\$H) multi-site study team and study participants for their time and valuable insights on the topic of ethical incentives in HIV research participation
- ❖ HIV+Aging Research Project-Palm Springs (HARP-PS) and our national community advisory board for guiding us to center participant perspectives at every stage of the research process



Ethical Incentives and Stakeholder Concerns

**Thank you!**

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