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Crucial but Understudied: Incentives in Hiv Research

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It is very likely that the same will apply to HIV prevention in women.

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I declare no competing interests.

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Crucial but understudied: incentives in HIV research

In this issue of *The Lancet HIV*, Katherine Kranzer and colleagues¹ report that economic incentives for caregivers in Zimbabwe increased uptake of HIV testing and counselling by children aged 8–17 years compared with caregivers with no financial incentive. HIV testing of groups that are hard to reach is a formidable challenge worldwide, and innovative strategies to reach adolescents in particular are crucial to reaching UNAIDS' 90-90-90 goals.²

These results provide further evidence of the importance of incentives to motivate research participation (in this case, receiving an HIV test) as part of a large community-based household survey. Still, the question remains as to what incentive amounts are appropriate, inadequate, or excessive.³ Although the issue of undue inducement might be less problematic in routine care (HIV testing) versus early phase, riskier HIV-cure research, the issue is the same: the process leading to the study's incentive amounts are unknown. For example, were community members or the participant population consulted on the incentive decision? The volunteer community wants to have a say on the type and amount of financial incentives in HIV research.⁴ Engagement with participants on the topic of payment is just one of the many types of consultation that should occur in research.⁵ In short,

this includes engaging the participant community beforehand, collaboratively pursuing research ideas that address a topic that is important to the community, using methods that are acceptable to community, and involving community input and leadership in every phase of the project.

In the present study, the fixed US\$2 incentive is about 2% of the average monthly income (\$100) of study households, meaning that \$2 approaches the daily household income. The \$10 lottery is about 10% of the monthly income. Although payment cannot be considered a benefit from the regulatory perspective, study participants nonetheless often consider financial incentives as a benefit received in exchange for study participation.⁶ This might be even more salient in resource-limited settings.

Another issue worth further exploration is the sustainability of economic incentives for HIV testing in a non-research context. Payment is a strong motivator for caregivers to have their children tested for HIV, but it remains to be seen whether the approach will work in a programmatic setting. Additionally, payment for HIV testing in a research study could generate unrealistic expectations about receiving such payments when the study ends, potentially leading to refusal of non-compensating HIV testing. In fact, some researchers⁷



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have shown that incentives might not be able to overcome important barriers to care.

A third issue is the use of payments to incentivise caregivers to get their children tested for HIV. Although payment was not concealed from the children, whether the children received any portion of the payment is unknown, although it was the children who received the HIV test. This approach was entirely appropriate in this context, but raises unique ethical concerns with respect to providing financial incentives to children, including payment possibly unduly influencing their decision making or that of their parents.⁸ However, if a nominal amount of money can help get hard-to-reach people tested for HIV and treated if indicated, there could be large, long-term savings in medical costs by treating those with early HIV disease sooner rather than later and by averting onward transmission if these patients are virally suppressed.⁹

Use of financial incentives to support participation in HIV research is standard practice, and Kranzer and colleagues present a compelling case for incentivised programmatic HIV testing. Additionally, recent evidence¹⁰ supports the use of financial incentives to increase viral suppression and clinic attendance in people living with HIV and to improve treatment adherence in patients with substance use disorders.¹¹ These are good and desired outcomes for patients. Nonetheless, the ethical issues of incentive use in this and other types of HIV research, especially research with greater risks such as HIV cure research, warrant deeper exploration.

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Preventing tuberculosis-related death in children with HIV

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In 2015 there were an estimated 1 million new cases of tuberculosis in children.¹ During 2010, it was estimated that in some sub-Saharan countries with high HIV prevalence, more than 20% of tuberculosis cases occurred in children.² In a meta-analysis, the pooled case fatality ratio in HIV-infected children receiving tuberculosis treatment but not antiretroviral therapy (ART) was 14.3%, compared to 3.4% in individuals receiving both tuberculosis treatment and ART.³ Marcy and colleagues⁴ describe high mortality (19%) in ART-naive HIV-infected children presenting for care with suspected

intrathoracic tuberculosis. The authors categorised children by use of consensus definitions, which included clinical, microbiological, and radiological criteria, as having confirmed, unconfirmed, or unlikely tuberculosis. Tuberculosis treatment of children with confirmed or unconfirmed disease was associated with substantially lower mortality ($p < 0.0001$). Early ART was similarly associated with reduced mortality (hazard ratio=0.08).⁴

This study was done in two African and two Asian countries, and few children (<4%) were lost to follow-up.⁴ However, as this was an observational study and