

Unintended and Intended Implications of HIV Cure Research: A Social and Ethical Analysis

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Scientific advances suggest the possibility of curing HIV infection, fundamentally reframing how a variety of stakeholders understand HIV. Coming to terms with this shift requires new thinking about not only HIV as a disease that can be cured, but also about HIV as an illness that can be healed. Theoretical frameworks that reach beyond the biomedical alone are necessary to engage and inspire a highly effective HIV cure. The development of HIV cure research may alter social relationships and health systems designed to control HIV. In partnership with our NIH R01 team and an exceptional multi-disciplinary group of HIV research leaders, we developed multi-disciplinary theoretical frameworks to better understand the implications of curing HIV and identified fundamental research questions on the social science, ethics, and policy of curing HIV. This led to progress along three lines of inquiry: HIV cure conceptual issues; the ethics of undertaking HIV cure research trials across settings, including low and middle-income nations; and priorities for HIV stakeholder engagement.

- 1) *Conceptual issues:* Cure as a concept has a long lineage and historical context. Comparisons with past cure initiatives can provide lessons and help develop research questions. The history of developing acute lymphoblastic leukemia cures in children and syphilis cures in adults may shed light on the meanings and policy implications of curing HIV infection. Given the current uncertainty of the clinical science and the likely long road ahead before a cure is available for chronically HIV-infected individuals, there should be caution about using the term “cure” in clinical settings. The concept of HIV remission may be easier to understand and more consistent with the state of the science.
- 2) *Ethics of undertaking HIV cure research trials across diverse settings:* An empirical analysis of informed consent tools used in ongoing HIV cure research trials suggested that adapting existing ethical guidance from other clinical disciplines (genetics research ethics regarding uncertain risk/benefits; psychiatric research ethics literature on structured treatment interruptions; and HIV research ethics literature on community engagement and participation in research) would be more useful than creating an separate set of HIV cure-specific research ethics guidance. The diverse ways in which unclear and sometimes unknowable research risks were communicated suggest areas for improvement. Further consideration of the ethics of recruiting individuals with acute HIV infection and newborns is important given their vulnerable status and relatively fewer latently infected cells.
- 3) *Priorities for HIV cure research stakeholder engagement:* Preliminary qualitative research in South Africa and China suggests that HIV-infected individuals have great hopes for an HIV cure and this optimism may enhance HIV testing programs. The implementation of early HIV cure research among individuals with acute HIV infection could synergize with public health efforts focused on detecting and preventing transmission in this subgroup. Examining the history of stakeholder engagement in other new HIV interventions such as pre-exposure prophylaxis can help us to improve the process of stakeholder engagement. We proposed a stepwise pathway for engaging HIV stakeholders to ensure that they are involved and aware of HIV cure research as it progresses through clinical trials.

Further theoretical and empirical social science research are urgently needed to guide clinical HIV cure research, ensure the ethical conduct of trials moving forward, and prepare policymakers. A strong social science and ethics research agenda is an essential component of a comprehensive plan for curing HIV.