

EXPERIENCES AND EXPECTATIONS OF PARTICIPANTS COMPLETING HIV CURE FOCUSED CLINICAL TRIALS

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Background: Understanding expectations and experiences of people with HIV participating in 'cure-focused' clinical trials will improve the design of future studies and the process of informed consent. We have previously reported on participants completing one cure focused trial and this study extends that work to a group completing 3 trials.

Methods: Participants were receiving antiretroviral therapy (ART) and had completed trials examining the effects of Vorinostat or Disulfiram on latent HIV, or how Dolutegravir impacts residual replication. Participants completed a survey on trial satisfaction and desirability of two scenarios: 1) Being completely cured, able to stop ART and visits for HIV care, and, 2) HIV still present, doctor visits required, but ART could be ceased without rebound viremia. Participants also ranked the importance of five cure scenarios: stopping ART, stopping doctor visits, not able to transmit HIV, unable to be re-infected with HIV, and being considered someone without HIV. Responses were compared by Wilcoxon signed-rank (sterilizing vs. functional cure) and Kruskal–Wallis (five potential benefits) tests

Results: Sixty-eight participants (96% male, mean age 48 years) completed the survey, (20 Vorinostat, 10 Disulfiram, 38 Dolutegravir). For potential cure scenarios, 96% rated scenario 1 very desirable compared to 58% for scenario 2 ($p < .01$). When ranking five potential benefits of cure, greatest importance was placed on stopping HIV transmission (46% 'most important', 3% 'least important') and least importance on stopping doctor visits to monitor HIV (3% 'most important', 44% 'least important') ($p < .01$ comparing all five scenarios).

Conclusion: The overwhelming majority of participants in cure-focused studies rated a 'complete' or 'sterilizing' cure as more desirable than a scenario of HIV remission. The potential benefits of not transmitting HIV was considered most important. Understanding participant expectations in this field of research allows investigators to more clearly discuss the rationale for these studies and potentially improve study design.

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Fig 1. Perspective on HIV cure if it could be achieved (n=68)

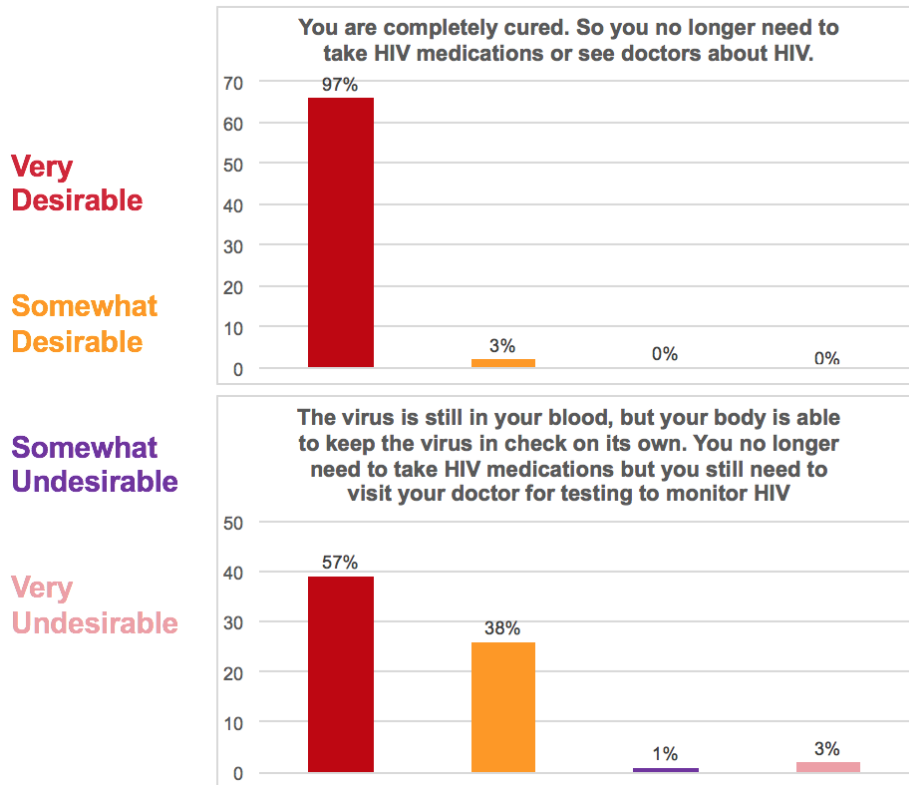


Fig 2. Ranking of 5 different potential cure scenarios from most important (1) to least important (5) (n=68)

