

## People willing to risk near-certain death for an HIV cure

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Nearly one-quarter of people living with HIV were willing to risk near-certain death in a clinical trial, if volunteering for the trial would help find a cure for the disease, according to the new study "HIV Cure



## Research."

"I am not going to live forever," said one interviewee, "it is about the next man, the next woman, and you have to have the mindset to care about people, which I do." Another interviewee said, "I'm willing to go the course for the cure and for the HIV community. I can't imagine how many people's lives would change if there was a cure." The authors of the study write that if people living with HIV are permitted to enroll in risky HIV cure trials, there need to be additional ethical safeguards. They concluded that this does not mean that people should be allowed to participate in research that is "sure to kill them," but that patient preferences should play a strong role in research that involves risk of harm.

In "Safeguarding Participants in Psychiatric Genetic Research," the authors write that genetic and psychiatric research may elicit "exceptionalism," the belief that these types of research deserve special protections. They find that patients and <u>family members</u> view safeguards as more important than other stakeholders do, creating implications for research participation and informed consent.

And in "Including Pregnant Women in Clinical Research," Pamela Payne proposes guidance for including pregnant women in research. Scanty evidence exists for the safe and effective use of medications for women that they may need to treat health issues during their pregnancies. Payne writes that researchers should justify, not presume, exclusion of pregnant women from research trials.

**More information:** Allison Kratka et al, HIV Cure Research: Risks Patients Expressed Willingness to Accept, *Ethics & Human Research* (2019). DOI: 10.1002/eahr.500035



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