

Misunderstanding surrounds HIV vaccine trials

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Better communication is needed around HIV vaccine trials to ensure those in at-risk communities understand the process and continue to participate, according to a new University of Toronto study.

The study – published in the September edition of the *American Journal of Public Health* – centred around a major international [HIV](#) vaccine trial that was called off before completion in 2009. Researchers wanted to know what individuals in high-risk communities understood about the trial and its termination, and how that impacted their willingness to participate in and support future research.

"In order to find a vaccine for HIV, it's essential to have the participation of those in at-risk communities for [vaccine trials](#)," says lead author Peter A. Newman, Professor at U of T's Factor-Inwentash Faculty of Social Work. "Our study showed that we're not doing enough to adequately communicate the processes and outcomes of HIV vaccine trials to most-at-risk populations. There is still a lot of misinformation, distrust and misunderstanding out there, which could ultimately lead to people in high-risk communities refusing to participate in trials."

In Toronto and Ottawa, researchers interviewed nine focus groups made up of people from "high-risk" communities. They asked participants about their knowledge of vaccines and vaccine trials – including the cancelled international trial – and probed their understanding of why that trial was called off. Researchers also questioned participants about their willingness to participate in future trials.

A few key themes emerged, according to Newman, who holds the Canada Research Chair in Health and Social Justice at U of T:

- Many people still believe that vaccine trials involve injecting a small amount of HIV into participants, a falsehood that could affect their willingness to participate in vaccine trials.
- There is a distrust of doctors and medical researchers. The international vaccine trial was called off when researchers discovered a small subset of participants were placed at a higher risk of contracting HIV, but many people didn't believe this was an unforeseen consequence. Some participants believed the doctors/researchers must have been able to predict this consequence, and this reinforced their distrust in the medical system.
- There is some confusion surrounding why HIV vaccine trials target people in high-risk communities. Some study participants saw this as unfair, from a social justice perspective.

"We found that there is a general altruism towards HIV vaccine trials in these communities, and a feeling that people should participate 'for the greater good,'" says Newman. "But there is also a lot of overriding confusion and misunderstanding, which illustrates a clear need for medical researchers and health professionals to do a better job of communicating with at-risk communities before, during and after trials."

Newman will present related findings at this year's annual AIDS Vaccine Conference in Bangkok between September 12 to 15.

Provided by University of Toronto

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