

## **Assessing factors affecting participation in HIV cure-related research: Implications for effective and ethical implementation**

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Abstract

The data collected and analyzed within the context of this dissertation project contribute to the emerging body of knowledge about factors affecting entry of people living with HIV in HIV cure-related research.

This DrPH dissertation project: 1) Examines whether perceived risks and benefits of studies act as deterrents and motivators of participation using a semi-structured survey; 2) Explores how various stakeholders perceive risks and benefits of HIV cure-related studies using qualitative methods; 3) Seeks to understand some of the pragmatic issues affecting participation in and implementation of HIV cure-related studies using qualitative methods.

Key survey findings include: • Willingness to participate in HIV cure-related research is high, but may not translate into actual research participation. • Although HIV cure studies confer no expectation of direct benefit, potential volunteers may still perceive the likelihood of benefits when deciding to join studies. Psychosocial factors, such as feeling good about contributing to the biomedical HIV cure-related research agenda, should not be under-estimated when planning studies. • More education is needed around risks and benefits of HIV cure research.

Key qualitative findings include: • Factors affecting participation in HIV cure-related research are multi-faceted. Main motivators related to the desire to contribute to HIV cure science. Altruism also plays a significant role. • It is possible to derive factors that facilitate recruitment and retention of study participants in HIV cure-related studies, as well as effective and ethical implementation of research.

Plan for Change: Drawing from principles of research ethics, implementation science and leadership theories, the plan for change focuses on the need to avoid unintended consequences during HIV cure-related research implementation. There are five main elements of the plan for change: summation of research findings in usable format, community engagement and coalition building, considerations and tools to facilitate the implementation of HIV cure research, development and implementation of an HIV cure research training curriculum (the “CUREiculum”) and possible avenues for future research.