Altruism and medical advice are key factors in decision-making about participating in HIV cure research: results from a UK-wide survey of people living with HIV

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INTRODUCTION

• The importance of patient involvement in the conception and design of HIV research has long been recognised.

• Early-phase HIV cure research is an especially important area to get patient input, with its exploratory nature, uncertain risks, and low likelihood of personal benefit.

• Exploring patient interest in HIV cure research, particularly expectations, motivations for participating, and factors involved in the decision-making is important to inform future recruitment efforts.

METHODS

• A self-completed web-based survey on patient attitudes towards HIV cure research participation was developed as part of a collaboration comprising CHERUB UK and HIV positive community groups, clinicians and government organisations.

• The survey was completed by PLHIV between June and November 2014. Participants were recruited online through social media, national and international HIV websites, advocacy forums, and in UK HIV clinics.

• The survey included demographics, desirability rating of types of HIV cure, current health and willingness to take part in cure research.

• An optional free-text box at the end of the survey elicited a large and detailed response from many participants. Themes were identified from the survey topics and text was coded and analysed.

RESULTS

Demographics

• 982 people completed the full survey, and 26% (258) of respondents provided spontaneous comments at the end of the survey.

• 81% were male, 71% MSM, 71% white, 49% aged 45-64, median 9 years from diagnosis, and 90% on ART.

Type of HIV cure

• Few expressed a preference about type of cure, as an HIV cure in any form remains desirable.

  “My preferred cure option would be a total eradication due to the concerns over long term conditions and inflammation.”
  – white MSM, Spain

  “I would love to be able to stop taking the drugs and remain well with HIV infection under control (not necessarily HIV-free). After 15 years i may say that i am quite tired taking drugs every day.”
  – white Female, Bulgaria

  “I have had a undetectable viral load for three years and have no side effects. My health is very good… Yet finding a cure remains very important to me. I believe the reason a cure remains so important are social and psychological – rather than medical. The stigma that still surrounds HIV makes it hard for someone like myself to form a meaningful lasting relationship. It also eats silently on your self esteem.”
  – White UK, MSK

Willingness to accept personal risk

• Willingness to accept risk was connected to a sense of scientific and social altruism

  “I would happily take part in a “cure” study if it would benefit others. Knowing that my life would have had some purpose is worth the possible side effects.”
  – White bisexual male, UK

  “Though there are potential risks I do know that for me to have survived on HAART it is because someone took a risk and volunteered on a study. This is my time to volunteer for someone else and possibly for myself and those that are dear to me.”
  – Black African male, Zambia

  “I would be prepared to take almost any risks in the hope of finding a cure, and i am sure a lot of people feel the same way.”
  – White British female, UK

Participating without personal benefit

• Decision to participate depends on weighing up pros and cons, and having sufficient time and medical advice to make informed choice

  “Given that the current medication causes me little inconvenience or side effects then i think any participation in a study that involves possible risks would need to be considered carefully.”
  – White MSM, UK

  “Many people with HIV/AIDS are willing to participate for altruistic reasons, so clearly laying out the risks and not over promising benefits is crucial!”
  – White MSM, USA

  “I am 58 so I do not expect a cure but I have children and grandchildren and want to remove this disease hanging over their heads”
  – White UK, MSK

  “I have a positive child and I would happily take part in a cure trial so to give him the best chance of a normal living relationship as he matures.”
  – White British female, UK

Willingness to stop treatment

• Main concern is health – risking good health, or making bad health worse. Usually, for many this decision would be predicated on medical advice.

  “I would be happy to be advised by doctors with regards to staying off meds or going back on if they felt it was time to do so.”
  – White MSM, UK

  “This would not be a decision I would make myself, but rather one I would make alongside the Consultant carrying out the trial, and I would be advised by the guidance of that Consultant.”
  – White UK, MSK

  “Prior to putting myself at risk of rejection to any form of medicine due to a trial I would like a lot of information to weigh up pros and cons.”
  – Black African Female, UK

Conclusion

• A cure for HIV remains a research priority for people living with HIV, reflected by the high number contributing comments to the survey.

• The importance of patient-clinician trust in decisions about participating in HIV cure research is demonstrated, and highlights the need for clear and independent patient information.

• Altruistic reasons are the main motivator in decision-making for many potential participants, regardless of risks-benefits.

• The ethical implications of altruistic based expectations for participating in HIV cure research must be taken into consideration when designing recruitment for such studies.

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