

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT

Anti-retroviral treatment (ART) use and non-use: an anonymous online survey

[Participant selection and purpose of study]

You are invited to participate in an online survey of anti-retroviral treatment (ART) use and non-use. By assessing a number of clinical, personal, social and structural incentives, barriers and reasons that influence people's decision making regarding whether or not to use ART, we hope to deepen our knowledge about people's beliefs in and experiences of ART. This study will contribute to better clinical care and social support for people living with HIV. You have been selected to participate because you are 18 years or older and are currently living with HIV in Australia.

[Description of study and risks]

If you decide to participate, we would like you to complete an online survey. The survey contains a range of sections including socio-demographics, HIV infection and related conditions, adjustment to living with HIV, experiences of ART, beliefs and concerns about ART as treatment and as prevention, engagement with clinical care, perceived stress and social support, and quality of life.

The self-complete survey will take 30 to 45 minutes of your time. If you decide to participate, please click the "I want to take part in the survey" button at the bottom of this webpage.

If you experience any discomfort or distress during the survey, you can withdraw at any time by simply closing the webpage. To assist you, there is a list of free phone counselling services on our study website (<http://artuse.csrh.org/help.html>) and at the end of the survey.

We cannot and do not guarantee or promise that you will receive any benefits from this study. The study will help to improve management of HIV and other chronic diseases that require lifelong drug treatment.

[Confidentiality and disclosure of information]

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law.

The online survey is anonymous with no recording of personal names, date of birth, residential address or contact details. We plan to publish the results in people living with HIV (PLHIV) community feedback sessions, peer-reviewed articles and conferences. In any publication, information will be provided in such a way that you cannot be identified.

[Recompense to participants]

There are no costs associated with participating in this research project, nor will you be paid. Participation in this study is completely voluntary.

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, SYDNEY 2052 AUSTRALIA (phone (02) 9385 4234, fax (02) 9385 6648, email humanethics@unsw.edu.au). Any complaint you make will be investigated promptly and you will be informed of the outcome.

[Feedback to participants]

A summary of research findings will be posted online for free download at this study website and the website of National Association of People Living with HIV Australia (NAPWHA) at the completion of the study. Data will be presented in aggregated forms where no individual participant will be identified.

[Your consent]

Your decision whether or not to participate will not prejudice your future relations with the University of New South Wales and CSRH. If you decide to participate, you are free to withdraw or discontinue participation at any time without prejudice. Your data will then be deleted.

If you have any additional questions, Dr Limin Mao (phone: (02) 9385 4482, email limin.mao@unsw.edu.au) will be happy to answer them.

To keep a copy of this Participant Information Sheet, you can download it here (<http://artuse.csrh.org/pi.pdf>) or print it.