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**ACES-LBTM+**

**The acceptability of self-testing for cervical screening in individuals who who identify as LGBTQIA+**

**Participant Information Sheet (PIS)**

You are being invited to take part in a survey to explore whether a self-test would be acceptable for cervical screening in individuals who identify as LGBTQIA+ (lesbian, gay, bisexual, transgender, queer, intersex, asexual plus). The research findings will form part of a PhD degree. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part, and discuss it with others if you wish. Please ask the contacts listed at the end of this document if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

**About the research**

* **Who will conduct the research?**

Professor Emma Crosbie and Dr Jennifer Davies-Oliveira from the Division of Cancer Sciences at the University of Manchester are conducting the survey.

* **What is the purpose of the research?**

Cervical screening is a test to help prevent cervical cancer and can save lives, yet only 7 in 10 eligible people in the UK attend screening, the lowest rate in 20 years. Cervical screening involves collecting cells from the cervix (neck of the womb) with a soft brush, known commonly as a ‘smear’. These cells are tested for a virus known to cause cancer called human papillomavirus (hpv). If hpv is detected, the cells are examined under the microscope. If they look abnormal, you are referred to a colposcopy clinic, where cells that are found to be ‘pre-cancerous’ (cells with potential to become cancer cells) are identified and treated before they get a chance to turn into cervical cancer.

Uptake for cervical screening is lower within the LGBTQIA+ population than in the heterosexual and/or cisgender population. Multiple barriers have been described to accessing cervical screening. Self-taken tests have been developed for use in cervical screening and could remove many of the current barriers. They have the potential to save lives by increasing the number of individuals who go for cervical screening by enabling earlier detection and treatment for precancerous cells.

The purpose of this survey is to explore current thoughts on different forms of testing for cervical screening, exploring barriers to screening and the acceptability of self-testing as an alternative to current cervical screening.

* **Am I suitable to take part?**

We invite anyone who has a cervix, identify as LGBTQIA+ and are 16 years old or over to complete the survey.

* **Will the outcomes of the research be published?**

We aim to disseminate the results at an organised event within the LGBTQIA+ community in 2022. The results of the survey will be published in a scientific journal and PhD thesis. You will not be identified in any reporting of the survey results.

* **Who has reviewed the research project?**

This survey has been reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This survey has been reviewed and given a favourable opinion by The University of Manchester Proportionate Research Ethics Committee (Ref: 2021-12901-21603).

* **Who is funding the research project?**

The survey is sponsored by the University of Manchester and has been partly funded by the Manchester Academic Health Science Centre (MAHSC).

**What would my involvement be?**

* **What would I be asked to do if I took part?**

If you decide to take part you can access the survey via the following link or QR code.



<https://www.qualtrics.manchester.ac.uk/jfe/form/SV_5BANoVvuatpwqOy>

The survey will take approximately 15 minutes to complete. You will be asked to tick several boxes to confirm that you are happy to participate in the survey. Each section of the questionnaire is described before any questions are asked.

There are no immediate benefits to taking part in this survey. We will use the results to help us know whether a urine hpv test is acceptable to those who identify as LGBTQIA+. This could encourage more individuals to participate in cervical screening in the future.

We do not expect you to experience any negative effects by taking part in the survey. However, some of the topics discussed may be sensitive to some individuals. If you feel that you would prefer not to answer some questions there will be an option for you to do this so you can move on and complete other questions in the questionnaire.

* **Will I be compensated for taking part?**

You will not receive financial compensation for your time. However, you will be asked if you want to enter a raffle (3 prizes of a £20 voucher) by voluntarily entering your email address at the end of the survey.

* **What happens if I do not want to take part or if I change my mind?**

It is completely your choice whether or not to take part in completing this survey. You are not obliged to do so. If you decide you would like to part and input your answers into the survey, we are unable to remove your data. This data is anonymised. Any identifiable information including your name is not stored.

If you do input your email address then we can remove this at any time at your request. Any data linked with an email address can be removed within 2 weeks of survey completion. This does not affect your data protection rights.

If you would like to withdraw from the survey please contact Dr Jennifer Davies-Oliveira (contact details at the end of this document).

**Data Protection and Confidentiality**

* **What information will you collect about me?**

The survey is set up so that no compulsory “personal identifiable information” (such as IP addresses & location data) is stored at any point.

Your email address is requested for two different reasons and is optional:

1) Entry into the raffle prize 2) Consent to be contacted for participation in future research.

* **Under what legal basis are you collecting this information?**

Your personal identifiable information will be stored in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

* **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. If you provide your email address, you can request a copy of the information we hold about you.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](http://documents.manchester.ac.uk/display.aspx?DocID=37095).

**Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

The study team at The University of Manchester will have access to your email address (if entered). Your details will be separated from your survey responses and be stored within an encrypted file on a secure drive at The University of Manchester at all times. Access to this information will be restricted to members of the research team only. We will store your email address for five years following the completion of the survey.

If you provide an email address consenting to be contacted for future research you will be able to opt out by responding to any communications stating your wish to unsubscribe. We will not contact you more than two times via your email address regarding future research opportunities.

**What if I have a complaint?**

 If you have a concern or complaint that you wish to direct to members of the research team, please contact:

* **Emma Thorpe (Programme Manager), Email - emma.thorpe-2@manchester.ac.uk**
* **Prof Emma Crosbie (Chief Investigator), Email - emma.crosbie@manchester.ac.uk**

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

**Research Ethics Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Email. research.complaints@manchester.ac.uk or Tel. 0161 275 2674**

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to the Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner’s Office about complaints relating to your personal identifiable information at https://ico.org.uk/make-a-complaint/your-personal-information-concerns/ or Tel. 0303 123 1113

**Contact Details**

If you have any queries about the survey or if you are interested in taking part then please contact the researcher(s):

**Dr Jennifer Davies-Oliveira (Clinical Research Fellow),
Email – jennifer.davies-oliveira@manchester.ac.uk**

**Emma Thorpe (Programme Manager), Email - emma.thorpe-2@manchester.ac.uk**

**Prof Emma Crosbie (Chief Investigator), Email.emma.crosbie@manchester.ac.uk**

Thank you for taking the time to read this information and considering whether or not you would like to take part in this survey.