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Enhancing Equity in Cervical Screening for People with Disability

PARTICIPANT INFORMATION STATEMENT

(1) What is this consultation about?

You have been invited to participate in this consultation on cervical screening. It will take place as a one-hour focus group held online via Zoom or in person at the University of Sydney, and it will include interviews and related activities.

You have been invited to participate in this consultation because you are a woman or a person with a cervix, with lived experience of disability and are eligible for cervical screening. This Participant Information Statement tells you about the consultation. Knowing what is involved will help you decide if you want to participate. Please read this sheet carefully and ask questions about anything you don't understand or want to know more about.

Participation in this consultation is voluntary.

By giving your consent to take part in this consultation, you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the consultation as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

(2) Who is running the consultation?

The consultation is being carried out by the project team:

- Professor Deborah Bateson (The University of Sydney)
- Associate Professor Mary Ann O'Donovan (The University of Sydney)
- Emily Gosden-Kaye (The University of Sydney)

The Australian Government Department of Health and Aged Care is funding this consultation.

(3) What will the consultation involve for me?

You will participate in a one-hour focus group interview with four other participants to answer questions about cervical screening. The focus group interview can take place online or in person at the University of Sydney.

The consultation activities will include examining a case study and discussing access to cervical screening. These discussions will be recorded and subsequently transcribed for internal reports.

(4) How much of my time will the consultation take?

The consultation will take approximately one hour.

(5) Who can take part in the consultation?

People and women with a cervix who have a lived experience of disability and are aged between 25 and 74, that are eligible for cervical screening.

(6) Do I have to be in the consultation? Can I withdraw from the consultation once I've started?

Being in this consultation is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney.

If you decide to take part in the consultation and then change your mind later, you are free to withdraw at any time. You can do this by writing to Emily Gosden – Kaye via emily.gosden-kaye@sydney.edu.au. If you withdraw before the focus group all of your data will be deleted, however you will not receive compensation from the consultation. If you withdraw after you take part in the focus group it not be possible to withdraw your responses, but your data will be deleted, you will still receive compensation.

If you take part in a focus group, you are free to stop participating at any stage or to refuse to answer any of the questions. However, it will not be possible to withdraw your individual comments from our records once the group has started, as it is a group discussion.

If you decide to withdraw from the consultation, we will not collect any more information from you. Please let us know at the time when you withdraw what you would like us to do with the information we have collected about you up to that point. If you wish your information will be removed from our consultation records and will not be included in the consultation results, up to the point that we have analysed and published internal reports.

(7) Are there any risks or costs associated with being in the consultation?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this consultation. Although not expected if you do become personally affected by the participation in this consultation, then please contact

(8) Are there any benefits associated with being in consultation?

We cannot guarantee that you will receive any direct benefits from being in the consultation.

(9) What will happen to information about me that is collected during the consultation?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this consultation. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Consultation findings will inform internal reports, but you will not be individually identifiable in these publications.

(10) Can I tell other people about the consultation?

Yes, you are welcome to tell other people about the consultation.

(11) What if I would like further information about the consultation?

When you have read this information, Emily Gosden–Kaye (emily.gosden-kaye@sydney.edu.au) will be available to discuss it further and answer any questions you may have.

(12) Will I be told the results of the consultation?

You have a right to receive feedback about the overall results of the consultation. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one-page summary. You will receive this feedback after the consultation is finished.

This information sheet is for you to keep