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Out with Cancer' study: LGBTQI+ experiences of cancer and cancer care

Who is conducting the research?

The research is being conducted by Prof Jane Ussher from the Translational Health Research Institute (THRI), Western Sydney University, and is funded by the Australian Research Council.

What is the research about?

The Out with Cancer study is investigating lesbian, gay, bisexual, trans, queer and intersex (LGBTQI+) experiences of cancer and cancer care.

LGBTQI+ communities represent an "ignored epidemic" and a "growing and medically underserved population" in cancer care.

Previous research suggests LGBTQI+ communities experience a disproportionate cancer burden, and face unique psychosocial challenges, such as higher rates of cancer related distress and sexual concerns, lower levels of family support, difficulties in accessing general health care or cancer services, gaps in patient provider communication and lower satisfaction with cancer care. For adolescents and young adults with cancer (AYAs, 15-29 years), psychosocial challenges may be compounded, particularly for those defining their sexual and/or gender identities given risks of rejection and discrimination.

Recently, the American Society of Clinical Oncology recognised this health disparity and concluded there is "insufficient knowledge about the health care needs, outcomes, lived experiences and effective interventions to improve outcomes" for LGBTQI+ populations. As a result, health care providers and policy makers are ill-equipped to provide culturally competent advice or assistance to LGBTQI+ cancer survivors and their families.

How will it help children and young people with cancer and/or their families?

Information from the study will be used to develop better information and support for LGBTQI+ people with cancer and their carers, including for young LGBTQI+ people.

Who can take part?

You can take part in this study if you are:

1. LGBTQI+ people who have ever had cancer (aged 15y+) *LGBTQI+ includes people who are lesbian, gay, bisexual, transgender, queer, born with a variation in sex characteristics (intersex variation), and those who identify with other descriptor terms used in our communities.*
2. Partners, family members, friends and other carers (aged 15y+) of LGBTQI+ people who have ever had cancer AND/OR LGBTQI+ cancer carers (aged 15y+)

What will participants be asked to do?

Participants will be asked to take part in an online [survey](#) about their cancer or caregiving experiences. Participants then have the option of a follow-up interview to discuss their experiences in more depth. They can also take part in a further photo interview, using photos taken by them.

When and where is the research taking place?

This international study is a three year funded Australian Research Council Linkage project. The study is occurring between 2019 to 2022.

Who has reviewed this study?

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H12664.

How to find out more

If you would like to find out more about this study, please contact *Rosalie Power* at outwithcancer@westernsydney.edu.au

Please note that by asking for more information you are not committing yourself in any way.