Will my participation in this study be kept confidential?

Any personal or health information you provide will be kept private and confidential.

Investigators

A/Prof Moira O'Connor

A/Prof Georgia Halkett

Ms Megan Plaster

Ms Maureen Tan

RESEARCH APPROVAL

The research has been approved by Sir Charles Gairdner Hospital (PRN: RGS0000005179) and Curtin University (Ref number). It will be conducted according to the principles set out in the National Statement on ethical Conduct in Human Research, published by the NHMRC (©Commonwealth of Australia 2007). The statement has been established to protect the interest of people who agree to participant in human research studies.

More information can be found in the National Statement on Ethical Conduct in Human Research (2007) - Updated 2018 | NHMRC

FOR MORE INFORMATION, PLEASE CONTACT

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Curtin University

An exploration of young people and their families' relationships and emotional experiences of living with sarcoma.

YOU ARE INVITED TO TAKE PART IN THIS STUDY.

Little is known about the impacts of how living with sarcoma on the lives of young adults and families. The purpose of this study is to explore how a sarcoma diagnosis shape young people and families' relationships and experiences.

WHAT HAPPENS IF I DECIDE TO PARTICIPATE IN THIS STUDY?

If you agree to participate in the study, you will be sent an information sheet, consent form and a short questionnaire to complete.

If you choose to participate after reading the information sheet, and return the consent form, a researcher will contact you to arrange for an initial interview.
This interview should be no more than 60 minutes to complete.

WHAT ARE THE COSTS TO ME?

There will be no costs to you.

HOW LONG WILL I BE IN THIS STUDY?

The purpose of this research is to learn how family members and young people navigate living with a sarcoma diagnosis, Your contribution to the study will include 3 interviews, from diagnosis through to post-treatment.

The interviews will be conducted at a time and place that is convenient to you. It can also be online or over the phone.

If you are a young person living with a sarcoma diagnosis, you might like to contribute via visual diary entrees that will be kept private and confidential. There will be an opportunity to be part of a photo exhibition if you choose to.

DECISION TO PARTICIPATE

Your decision to participate in this study is voluntary. You may decide to be in this study or not take part in it at all. If do you decide to participate, you are able to change your mind at any time during the study.
Any decision you make will not affect your regular medical care or any benefit to which you would otherwise be entitled.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART, TO ME AND TO THE WIDER COMMUNITY?

While you may not personally benefit from participating in the research, You may benefit from the opportunity to speak about your experience, knowing the information you are sharing regarding your expriences may:

- assist Health care professionals and support services understand what matters to young people and families who are living with a sarcoma diagnosis.
- be used to improve the quality of care for other young people and families who may go through the same experience of navigating a sarcoma diagnosis.

WHAT ARE THE POSSIBLE RISKS OF TAKING PART?

You may feel that some of the questions we ask are stressful or upsetting. You can choose to skip the question, or withdraw from the study without having to give a reason. We will provide information for support services you can contact if needed

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study.