Help me, help you: The role of friends in supporting young people with cancer.

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	*HRE2022-0167*
Project Title:	*Help me, help you: The role of friends in supporting young people with cancer.*
Chief Investigator:	*Professor Peter McEvoy, Professor of Clinical Psychology*
Student researcher:	*Rebecca Sampson*
Version Number:	*1.1*
Version Date:	*05/APR/2022*

What is the Project About?

Young people (16-25 years) with cancer face unique challenges when compared to other age groups with cancer as they must navigate the developmental demands of adolescence and young adulthood, while dealing with the challenges of diagnosis, treatment, and other stressors related to cancer. Therefore, sometimes young people may face more severe and enduring challenges compared to other populations with cancer, as well as compared to their physically healthy peers. Peer relationships are potentially an important resource to support resilience in this group, as peers play an important role in promoting positive youth wellbeing and development.
In this project we are working with Canteen which is an organisation that provides support to young people (12-25) impacted by a cancer diagnosis. Canteen's support options are currently available to young people with a cancer diagnosis, or a family member with a cancer diagnosis.

This research aims to understand

a) What young people with cancer want their friends to know about living with cancer, and how friends can best support them.
b) What friends would like to know about their friend's experience with cancer and what friends need to know to be able to support their friend with cancer.
c) How this align with Canteen's current resource "Wait… did you say 'cancer'?" and how this resource can be improved.

We are seeking to recruit 20 young people for this study.

Who is doing the Research?

The project is being conducted by Rebecca Sampson as part of a Doctor of Philosophy degree at Curtin University. The research is being supervised by Professor Peter McEvoy and Dr Vincent Mancini from Curtin University, Dr Amy Finlay-Jones from Telethon Kids Institute and Dr Pandora Patterson and Dr Fiona McDonald from Canteen Australia. The project is funded by Curtin University and Telethon Kids Institute in line with their student funding. There will be no cost to you, and you will be reimbursed with a $20 gift card for your time.

Why am I being asked to take part and what will I have to do?

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You have been invited to participate because you are a young person aged 16 to 25, living in Australia and you:

- Have a history of a cancer diagnosis or,
- Are a friend of a young person with history of a cancer diagnosis

Being involved in this study will require you to attend a one-on-one interview or focus group session conducted online on the Teams platform (so you will need access to a computer).

One-on-one interviews will last approximately one hour. Depending on whether you have a history of cancer yourself, or you have a friend with cancer, you will be asked either:

a) What you would like your friends to know about living with cancer and how they can best support you or

b) What you would like to know about you friend’s experience with cancer and what you need to know to be able to support your friend with cancer.

Focus groups, will take approximately two-hours. The same questions will be asked, however participants will be able to discuss their ideas as a group.

Once these data have been analysed, if you consented to being contacted about further participation, you will be invited via email to take part in a final focus group.

Prior to participation in this focus group, you will be asked to read Canteen’s resource “Wait… did you say “cancer”? which is available online or a physical copy can be posted to you. This focus group will take approximately two-hours. You will be shown the themes identified in the first round of interviews and asked if this reflects your experience. There will then be group discissions around the information in the resource and you will get the opportunity to share your opinions about the resource. We will ask guided questions around how useful you find the information in the resource, your opinion of how information presented in it, and how you think the resource could be improved.

We will make a digital audio recording of interviews and focus groups so we can focus on what you are saying and facilitate the discussion. After the interview or focus group, we will use the recording to make a full written copy.

This study is part of a larger project with two more studies. If you would be interested in participating in further studies, we would like you to consider allowing us to send you more information about these at a later time. If you choose to receive this information, it is then your choice to take part of not.

Are there any benefits’ to being in the research project?

You may find benefit from having the opportunity to share your thoughts and experience. Additionally, we hope the results of this research will allow us to develop a more relevant resource for friends of young people with cancer. We will also use the information to guide development of an online intervention to help friends of young people with cancer build their supportive communication skills to better support their friend with cancer.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

While we have taken steps to minimise the risk of distress, discussing your experience of being supported by friends or being a friend to someone with cancer may involve thinking about challenging times which can be uncomfortable. You are asked to only share what you are comfortable sharing, and you can choose to not answer any of the questions. If you experience distress or feel you need support if uncomfortable thoughts arise, please contact your GP or mental health professional. Alternatively, you can contact any of the services below for free.

Canteen's help options https://canteenconnect.org/	Access a counsellor for support online via Canteen Connect. Alternatively, talk to a health professional at over the phone.	1800 835 932
Headspace https://headspace.org.au/online-and-phone-support/	Confidential, free and secure space where young people 12 - 25 or their family can chat, email or speak on the phone with a qualified youth mental health professional.	(03) 9027 0100
Lifeline https://www.lifeline.org.au/	24/7 crisis support service for Australian's experiencing emotional distress.	13 11 14
Kids Helpline https://kidshelpline.com.au/	24/7 confidential counselling service available via WebChat, phone or email for 5 - 25 year old's.	1800 55 1800

Your will also be provided a debrief form via email which will include these contact numbers. If participants experience distress while discussing their experiences in a one-on-one interview we take a break, change the topic, or end the interview if needed. In focus groups, you can choose to take a break at any time by stepping away, leaving the meeting and re-entering later or leaving all together. Those who do decide to end the interview early or leave a group conversation will be followed up by a counsellor from Canteen via email. They will check in to see if you would like any further support. If you would like to speak to a counsellor afterwards please do not hesitate to reach out to myself or the any of the supervisors listed below.

Sometimes just thinking about your experience with cancer or a friend with cancer can be upsetting. If you choose not to take part in this research but feel distressed from considering it please contact Lifeline on 13 11 14.

Other than giving up your time and the effort of participation, we do not expect there to be any other inconvenience associated with taking part in this study.

Who will have access to my information?

Due to the nature of focus group participation, participants will see and interact with each other. You may even know some of the other participants. As the facilitator, I will remind participants about confidentiality of the discussions. Due to the potentially sensitive information, experiences, and opinions that others may want to share, all participants will be asked to keep information shared between the group. If you are concerned about confidentiality you may choose to opt for a one-on one interview.

Focus group data will be de-identified when the transcript is written. Interview data will be re-identifiable with a participant code until transcripts have been checked by the participant at which point any identifying information will be removed. There will be no identifying information used in analysis, reporting or publications. Data collected will be stored on Telethon Kids Institute share drive in a location that is only accessible to the research team. A back up will be stored on Curtin's secure R drive only accessible to the research team. The data will be stored securely for 7 to 25 years after the project is complete, at which time it will be destroyed, in line with Curtin HREC guidelines.

Any information we collect will be treated as confidential and used only in this project or by Canteen's research team unless otherwise specified. The following people will have access to the information we collect in this research: the research team, and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development. Additionally, your contact information may be shared with a Canteen counsellor if there is a wellbeing follow up required.

We will use the email address you return this consent form from to send you a voucher for your participation. This will not be linked to any of the data we collect.

Will you tell me the results of the research?

If you are interested in obtaining a summary of the results, please contact the researchers using the details below after October 2022. Results will not be individual but based on all the information we collect and review as part of the research. Results will be published in peer reviewed journals, presented at academic conferences and to non-academic audiences, shared in relevant newsletters and on Canteen's website.

Do I have to take part in the research project?

Participating in this research project is voluntary. It is your choice to take part or not. You do not have to agree if you do not want to. If you decide to take part and then change your mind, that is okay, you can withdraw from the project. If you choose to withdraw from the study before data analysis, we will remove the information you have provided. If you choose not to take part or start and then stop the study, it will not affect your relationship with Canteen.

If you take part in a one-on-one interview, you are free to withdraw from the study prior to approving your transcript. Workshop participants may choose to withdraw any time before the workshop date. After this we will be unable to remove your information as it will be recorded in an anonymous way.

What happens next and who can I contact about the research?

If you decide to take part in this research, we will email you a link to an online consent form. You will be asked to read and sign the consent form with an e-signature. By signing, you are telling us that you understand what you have read and what has been discussed. Signing the consent indicates that you agree to be in the research project and have your information used as described. Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

If you have any further questions, please contact Rebecca Sampson via email at rebecca.sampson@telethonkids.org.au. Alternatively, you can reach out to any of the supervisors using the contact information below.

Prof Peter McEvoy	(Curtin University)	peter.mcevoy@curtin.edu.au
Dr Amy Finlay-Jones	(Telethon Kids Institute)	amy.finlay-jones@telethonkids.org.au

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Dr Vincent Mancini	(Curtin University)	vincent.mancini@curtin.edu.au
Dr Pandora Patterson	(Canteen Australia)	pandora.patterson@canteen.org.au
Dr Fiona McDonald	(Canteen Australia)	fiona.mcdonald@canteen.org.au

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2022-0167). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.