

Participant Information statement and consent form

HREC Study Number:	31089		
Short Name of Project:	CATS		
Full Name of Project:	The Child to Adult Transition Study (formerly known as the Childhood to Adolescence Transition Study)		
Principal Researcher:	Professor Susan Sawyer, Principal Investigator		
Version Number:	5	Version Date:	10/07/2023

Dear <insert participant's name>,

Thank you for taking the time to read this Participant Information Sheet. We kindly ask you to read the following information prior to deciding whether to participate. If you have any questions, you can contact the CATS team on +61 3 9936 6272.

What is the Child to Adult Transition Study (CATS) about?

The Child to Adult Transition Study (CATS) is a research project based at the Murdoch Children's Research Institute, which is located at The Royal Children's Hospital in Victoria. The CATS study focuses on the important transitions that young people go through during their life, including puberty, the move from primary school to secondary school, and the move from school into the workplace or further education. CATS aims to understand these transitions in order to develop programs to improve this period of life for future young people.

As with previous CATS surveys, the focus of this CATS survey will be on mental and physical health, education, work, and other important life activities and behaviours. This year you are invited to complete one online survey which will take approx. 25 minutes to complete.



Who is running this research project?

Professor Susan Sawyer is the Principal Investigator. She oversees the research project and the project team. Professor Sawyer is based at the Centre for Adolescent Health at the Murdoch Children's Research Institute (MCRI). Our campus partners are the Royal Childrens Hospital (RCH) and the Murdoch Children's Research Institute (MCRI). Funding for the project is currently provided by the National Health and Medical Research Council (NHMRC), RCH and MCRI.

Why am I being asked to participate?

You are being asked to participate because you are one of the original participants in CATS. CATS conducts its research by following the same group of young people for a long period of time to find out how things change for that group. This means CATS doesn't recruit new participants. You are therefore one of the only people that can participate in this study.

How do I participate?

You will be given an individual link and asked to complete an online survey. The survey will include questions related to your health, home life, relationships, use of alcohol, tobacco and other substances. There will also be questions related to the difficulties some people experience in their life while growing up, as well as exposure to violence within relationships and specific mental health consequences related to self-harm and eating disorders. Completion of the survey should take approx. 25 mins. A consent form to participate in the study was initially completed by a parent/guardian when you were a child. Now that you are an adult, if you have not already completed a consent form for continuing in the CATS study, you will be asked to do that also.

Are there any risks to participating?

While we don't think there are any significant risks to you in taking part in this study, we understand that there might be a risk of distress due to some sensitive questions. We have tried to make sure that the questions in the survey are appropriate but there may be a small chance that you become upset while completing the survey as it does include some topics that some people may consider sensitive. To minimise this, you will be informed at the beginning of the survey and prior to any sensitive sections that you do not have to answer any questions that you do not want to answer. You can also stop completing the survey at any time. If the survey questions raise any concerns to you, we encourage you to use the services in the resource sheet that will be provided to you at the beginning and during your survey. This resource sheet will have online and phone details for a number of resources which may be useful, if required. If the survey raises any concerns for you, you can also call the Project Manager on +61 3 9936 6272 or speak to a person with whom you feel comfortable. Upon completion of your survey, you will be provided with a \$40 gift card to thank you for your time and effort.

What are the possible benefits of participation?

You may not get any direct benefits from this project. However, this is an opportunity to be part of a study run by leading researchers at a world-class institution. By hearing from the same group of participants each year, we can advocate for young people and contribute to important policy decisions that directly affect your generation.

How will my information be used?

We will collect and use personal and health information about you for research purposes. Before using the information you provide it will be deidentified. This means we will remove all personal identifiers from your information, including your name, date of birth and address. We will replace your name with a code number. This information will be re-identifiable but only authorised researchers who are working on this project will be able to re-identify your information by linking your code number to your name and other personal information.

How will my information be stored and kept secure?

We will store your electronic information securely on an internal server, under password protection. We will keep any paper copies of your information in locked storage. Your electronic and paper information will be stored at the Melbourne Children's. The Melbourne Children's includes The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics.

Only members of the research team and the Royal Children's Hospital Human Research Ethics Committee have will have access to the information collected as part of this research project. When we write or talk about this project, we will do so in such a way that no participant can be identified. Your survey data will not be kept with your personal information. This means that we will remove all names and contact information from your survey data. Your data will have a special code number. Only certain members of the research team can match your name to your code number, if it is necessary to do so.

You have the right to access and correct the information we collect and store about your child. This is in line with relevant Australian and/or Victorian privacy and other relevant laws. Please contact us if you would like to access this information.

Will my information be shared with anyone?

To advance science and public health, we may share your **deidentified** data with any current and future funders, research projects, biobanks (storage banks for biological samples), medical journals or data research repositories. Some of these organisations may be located overseas. **Any data that we send overseas is not be protected by Australian laws and regulations.** By signing the consent form you give us permission to do this.

If we share your data, we will remove identifying details such as your name, date of birth and address and give the data a special code number. Data will be transferred via a secure web platform, with a password to protect it. The data will be stored on the RCH server for a specified time to allow the researcher to retrieve it via a unique URL and password, usually up to 2 weeks, then the data will be removed after that specified date. Despite our best efforts, there is a small chance that you could be re-identified by someone outside of this research project. In the unlikely event that this happens, someone from the research team will contact you. If, at any point, you think that your data may have been re-identified, please let us know.

How long will my information be kept?

The information we collect as part of CATS is valuable. It may have benefit to future generations or provide important historical value. To be able to provide these benefits we will store the information we collect indefinitely.

Do I have to participate?

Participation in CATS is completely voluntary. You can choose whether or not to complete each survey, can skip questions you don't wish to answer, and can stop a survey at any time. You may skip one or several surveys if you prefer. You can also withdraw from the project at any time. Please just let us know.. You do not need to tell us why you are taking yourself out of the research project.

If you leave the research project, we will continue to use the information we have already collected about you. If you do not want us to use this information, please tell us. In this case, we will **stop using** your information in any future work. We may securely destroy the information as required by law.

If you have any questions about the project, you can contact the Project Manager on 03 9936 6672. You can also email us at cats@mcri.edu.au.

Thank you very much for your time.

Yours sincerely



Professor Susan Sawyer
Principal Investigator
The Child to Adult Transition Study
Murdoch Children's Research Institute

You can contact the Director of Research Operations at The Royal Children's Hospital if you:

- have any concerns or complaints about the project
- are worried about your rights as a research participant
- would like to speak to someone independent of the project.

The Director can be contacted by telephone on (03) 9345 5044.