

# Information

## FOR STUDY PARTICIPANTS



Dear Participant,

Since 2012 you have been one of 1239 Victorian school students who participate in the Childhood to Adolescence Transition Study (CATS), a long-term research project conducted by the Murdoch Children's Research Institute. The study involves doing yearly surveys in school or at home. You may have also provided some saliva samples in primary school and late high school.

CATS is now continuing with a slightly different name: The Child to Adult Transition Study. The information below gives you more information about CATS and asks if you would like to continue participating. Taking part in the study is up to you. You can say no if you want to.

### 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 study looks at what allows children and young people to have a healthy transition to adulthood. It focuses on the important transitions that young people go through during this journey, 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 future CATS surveys will be on mental and physical health, education, work, and other important life activities and behaviours.

### 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.

Study Number: 30189  
Short name of Project: CATS  
Full Name of Project: The Child to Adult Transition Study (formally known as the Childhood to Adolescence Transition Study)  
Principal Researcher: Professor George Patton, Principal Investigator  
Version Number: 2  
Version Date: 08/04/2022

## How do I participate?

As in the first ten years, CATS will continue to send you online or postal surveys. This may be once a year as we have done previously, or it may be a number of years in-between surveys. In either case the CATS team will notify you.

## Are there any risks to participating?

Some of the questions we ask are about topics that some may consider sensitive. You can skip any questions you don't wish to answer. There is a small chance that you might become upset while you are completing one of our surveys. If this happens, you can take a break from the survey. We can provide contact information for services that may be able to help. We can arrange to remove questions about similar topics from future surveys. You may also decide to withdraw from the project.

Taking time to complete our surveys may be inconvenient for some people. To thank you for your time we will provide a thank-you gift. The value of this gift will change as appropriate based on the length of each survey.

## Who is funding CATS?

This project has been supported by a number of sources since it began in 2012. It is currently funded by:

- The National Health and Medical Research Council (NHMRC)
- The Australian Government Department of Education, Skills and Employment (DESE)
- The Victorian Department of Education and Training (DET)

It is possible that we may receive funding from government organisations or commercial companies in the future. This funding would cover the costs of research. If we get more funding, we may need to share your deidentified information with the funder. If so, we will do this in a way that protects your privacy. See more about this below.

## 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. 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?**

In this project, we will store your electronic information securely on an internal server. 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.

### **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 this consent form you are giving 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. We will use a web-based application to securely transfer your data to other people. We will send each recipient a unique URL to download the data file, then separately send the password for downloading the data file. The data file will be stored securely on a server and then removed from the server after a specified expiration date (always within 14 days).

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 you 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. You just need to tell us so. We will let you know if there is anything else you need to do. You do not need to tell us why you are taking yourself out of the research project.

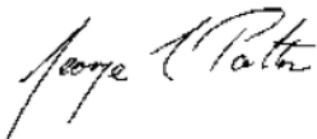
If you leave the research project, we will continue to use the information we have already collected about you. If you do not want us to use this information, please tell us. In this case, we will stop using your information in any future work. We may securely destroy the information as required by law.

The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics are research partners. Together, they form the Melbourne Children's Campus. As research partners, they can share research information with each other.

If you have any questions about the project, you can contact Elissa Phillips on 03 9345 6732. You can also email them at [cats@mcri.edu.au](mailto:cats@mcri.edu.au).

Thank you very much for your time.

Yours sincerely



Professor George Patton  
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.