

Plain Language Statement

**Melbourne School of Population and Global Health
Centre for Health Equity
Faculty of Medicine, Dentistry and Health Sciences**



Project:

How happy are you? Self-reported perceptions of personal wellbeing by adults diagnosed with a congenital disorder of the corpus callosum

Maree Maxfield (PhD candidate) Tel: +61 428 579 216

Email: m.maxfield@student.unimelb.edu.au

Professor Keith McVilly (supervisor) Tel: +613 8344 5366

Email: keith.mcvilly@unimelb.edu.au

A/Professor Helen Jordan (cosupervisor)

Tel: +613 9035 8228

Email: h.jordan@unimelb.edu.au

Dr Alexandra Devine (co-supervisor)

Tel: +61 415 570 109

Email: alexandra.devine@unimelb.edu.au

Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this research.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can also stop at any time.

What is this research about?

This research is about finding out about the quality of life and personal wellbeing for adults diagnosed with a disorder of corpus callosum (DCC). This can also be described as 'happiness' with life. A disorder of the corpus callosum means that a person is born without all or part of their corpus callosum, the nerve fibres joining the two halves of the brain. Adults with full agenesis, partial agenesis, dysgenesis or hypoplasia of the corpus callosum will be able to take part.

We would like to find out how the impacts of having this disorder may affect quality of life.

We particularly want to find out how adults with a DCC rate their own personal wellbeing. There has been very little prior research to help understand the lives of adults who have a DCC and what contributes to or hinders their personal well-being and happiness in life.

What will I be asked to do?

If you agree to take part in this research you will be asked to take part in an interview or online survey, beginning with some optional questions about your yourself and your demographics. These may include information such as your age, your diagnosis, gender, NDIS status, employment status, educational level, income, where you live, your connections to community and the option to add any other information you wish to share.

Next you will be asked to complete 8 short questions about your personal wellbeing or quality of life.

There are no right or wrong answers. It is completely about your own experiences as you have lived them. The questions will include: how happy are you with your life as a whole; and how happy are you with the things you make and do?

There are a few different ways to choose how you take part. You can choose either:

1. a face to face interview with Maree at a time that suits you
2. an online Zoom interview with Maree at a time that suits you
3. a phone interview with Maree at a time that suits you
4. an online survey via Zoom, at a time that suits you

The interview or survey will take less than one hour and you may stop at any time.

If you choose to do the interview in person you can bring a friend or family member to the first part of the interview. However, you will need to answer the questions about your quality of life by yourself. At this time, it will only be you and Maree in the room. Maree will not tell anyone else what you have said about your quality of life unless you give specific permission for her to share that information.

What are the possible benefits?

This research may not have any immediate benefits for you, apart from giving you an opportunity to be heard by giving a first-hand account of your own quality of life. There is very little information available about how a disorder of the corpus callosum (DCC) affects the quality of life of adults.

The findings of this research may help to plan further projects that help to advocate for improved recognition and supports for all adults with corpus callosum disorders, particularly if it finds common areas of concern. For example, further research could assist with advising policy makers and health professionals what resources and supports are needed for independence, social inclusion, employment, education and the general health and wellbeing of adults with a disorder of the corpus callosum.

You will receive a \$20 gift card in appreciation of your time and willingness to participate.

What are the possible risks?

During an interview, it is possible that talking about your life experiences may be difficult and might stir up some emotions. If you feel uncomfortable, you will be free to take a break if anything upsets you. If there is a question that you don't want to answer, you don't have to and you can go on to the next question. If you want to stop the interview it can be stopped at any time.

Maree will provide you with a list of contact details about counselling and support services, to help cope with any emotional responses which are unexpected or overwhelming.

All names of participants will be changed when we report on the findings of the survey to maintain confidentiality. This means you remain anonymous and we protect your identity.

If Maree feels worried about your safety because of what you have said, she will help you to find the right person to tell and to get the help you need.

Do I have to take part?

No. Participation is completely voluntary. You may withdraw (quit) at any time without having to give a reason. If you withdraw during the interview or before analysis of information has begun, all your information and data will be destroyed.

Choosing to not participate or to stop participating, will in no way affect your relationship with Maree or any of your DCC community activities - you can continue with these as usual.

Will I hear about the results of this project?

A report will be written that summarises the key research findings. The report may be presented at a conference or published in a research journal. A summary of the report will be sent by email to all participants.

What will happen to information about me?

Any personal information you provide in the interview or survey will be confidential and will only be accessed by the researchers named at the beginning of this document. All digital and written files produced as a result of the interview or survey will be securely stored at Melbourne University, according to university regulations and then destroyed after five years.

Your contact details will be used to send you the report summary and ask you about any follow up research related to the findings of this study. You can stop contact at any time.

Is there any potential conflict of interest?

Maree is involved with the support community for DCCs in Australia and has a family member with a DCC. Strict ethical procedures will be in place to keep her roles of researcher and DCC community member separate. They will include reflecting on this position at all stages and consulting closely with supervisors and colleagues. Maree has past experience of conducting research with this community.

Where can I get further information?

If you would like more information about the project, please contact:

Maree Maxfield. Tel: +61 428 579 216 Email: m.maxfield@student.unimelb.edu.au

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne, No. 2021-20393-17872-2. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team and/or the name or ethics ID number of the research project.