Plain Language Statement

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

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Information about the research project and researchers

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

Research Team
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Information about taking part in the research
Thank you for being interested in this research project.

The next 4 pages will help you decide if you would like to take part.

You can ask for help to read this information. You may ask any questions if you would like more information.

You can choose whether you would like to take part or not.

If you begin to take part and change your mind you can stop at any time

What is this research about?

This research is to learn about the personal wellbeing of adults who have a disorder of corpus callosum (DCC). Personal wellbeing can also be described as happiness.

Someone who is born missing all or part of their corpus callosum has a disorder of the corpus callosum (DCC).

It may be called:
- partial agenesis,
- full agenesis,
- dysgenesis
- hypoplasia
- hyperplasia

There is not much information about the personal wellbeing of adults with a DCC.

We would like to ask adults with a DCC about their own personal wellbeing.

What will I be asked to do?

If you agree to take part you will be asked to answer some questions about yourself and your personal wellbeing.

There are no right or wrong answers. It is about your own life.

You can choose how you take part. You can choose either:

1. a face to face interview with Maree at a time that suits you, or
2. an online interview with Maree at a time that suits you

The interview will take about one hour and you may stop the interview at any time.

You can bring a friend or family member with you. When you answer the questions it will only be you and Maree in the room to protect your privacy.

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Maree will not tell anyone what you have said in the interview unless you give permission to share that information

What are the possible benefits?

This interview will give you a chance to say how you rate your own personal wellbeing

The findings of the research will help to understand how your personal wellbeing compares to other Australian adults.

The findings will help the research team to plan projects with adults with a DCC to explore ways of getting the best support services for you and others

You will receive a $20 gift card to thank you for taking part.

Are there any risks?
It may be upsetting to talk about your life.

If you feel uncomfortable, you will be free take a break or stop the interview at any time

Maree will give you a list of contact details for counselling and support services in case the interview stirs up emotions.

The research team will write your answers and remove your name. Nobody else will be able to know your answers. You will be anonymous.

Do I have to take part?
No. You can choose to take part or not.

If you don't want to take part or you want to stop at any time this will not change your relationship with Maree or the DCC community.

If you stop. You don't have to give a reason.

Will I hear about the results of this project?
Maree will send you a summary that tells you what the team found about the personal wellbeing of adults with a DCC.

The results may also be published or presented at a conference. They will also help to plan the next project.

What will happen to information about me?

Your name and contact details will be stored. We will contact you with the findings of the research We may ask if you would like to take part in the next project.

Only the Research Team will be able to see the answers you give in the interview. Written materials will be stored in a locked filing cabinet at Melbourne University.

Digital material will be stored on a laptop with a password or on the university's secure cloud storage system.

All the original materials will be destroyed after five years.

Is there any potential conflict of interest?

Maree has a family member with a DCC and she is involved with AusDoCC, the support organisation for corpus callosum disorders.

Maree will follow strict ethical guidelines to keep her research and AusDoCC roles separate. She will do this by keeping a research journal and thinking about each situation.

Maree will get advice from her university supervisors and AusDoCC leaders.

Where can I get more information?

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

Maree Maxfield (PhD candidate) Tel: 0428 579 216
Email: m.maxfield@student.unimelb.edu.au
or
Professor Keith McVilly (supervisor) Tel: 03 8344 5366
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or
A/Professor Helen Jordan (co-supervisor)
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Email: alexandra.devine@unimelb.edu.au

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

This research project has been approved by the Human Research Ethics Committee (HREC) of The University of Melbourne, Number 2021-20393-17872-2

If you are worried or want to complain about this research project and you do not wish to discuss it with the research team, please contact:

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 in confidence.

Please give the name of the research team or ethics ID number of the research project.

Thank you for reading this Plain Language Statement