



**HREC Project Number:** 70649

**Project Title:** **Informing the Psychological Care of Children and their Families in the Colorectal and Pelvic Reconstruction Service (CPRS)**

**Principal Researcher:** Dr Kim-Michelle Gilson, Department of Paediatric Surgery – Colorectal and Pelvic Reconstruction Service (CPRS)

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Dear Parent/Guardian,

We are inviting you to take part in the CPRS Psychological Care project.

### **1. What is the research project about?**

The Colorectal and Pelvic Reconstruction Service (CPRS) was established in 2019. It is a multi-disciplinary service that aims to deliver comprehensive clinical care to children and families with complex colorectal and pelvic conditions such as Anorectal Malformations, Hirschsprung Disease and Chronic Constipation. Team members include: paediatric colorectal surgeons, urologists, gynaecologists, gastroenterologists, a paediatrician, clinical nurse consultants, stomal therapists, a social worker, a psychologist, a child life therapist, and coordinator staff.

We would like to understand what support you think is important for you and your child's (or baby's) emotional wellbeing. This will inform the type of psychology help offered within the service. Delivering care that is responsive to the needs of families is a key part of the development of the psychological component of the CPRS.

There are very few research studies that look at what psychological support is needed to help the emotional wellbeing of children with complex colorectal conditions and their families.

This project aims to conduct interviews to provide an in-depth account of your experience and what help you think is needed to support you and your child's emotional wellbeing.

### **2. Who is running the project?**

This project is being led by Dr Kim-Michelle Gilson who is a Senior Clinical Psychologist at the RCH. The project team also includes Associate Professor Sebastian King (Colorectal Surgeon), Dr Misel Trajanovska (Research Coordinator), Dr Alice Morgan (Senior Clinical Psychology Coordinator), Dr Frank Muscara (Senior Neuropsychologist and Research Fellow). Other members of the team will include a student or research assistant who, under supervision of the lead investigators, will be involved in data collection and/or analysis.

The project will be taking place at the RCH and is funded by the CPRS.



### **3. Why am I being asked to take part?**

We are asking you to take part in this project because your child has a colorectal condition (Anorectal Malformation, Hirschsprung Disease or Chronic Constipation).

### **4. What do I need to do in this project?**

You will be asked to participate in an interview. The interview will ask you about your child and your journey of care at the hospital, so far. We are interested to hear about what you found helpful for you and your child's emotional wellbeing and what you found challenging. Also, how you think a psychologist could have helped your experience, so far.

A member of the CPRS research team will organise a time that is convenient for you to complete the interview. The interview can be completed at The Royal Children's Hospital or over the phone if you prefer. The interview will take approximately 45-60 minutes to complete.

We will audiotape the interview. This is so we can concentrate on listening to what you have to say rather than distract ourselves by taking notes. After the interview we will transcribe the recording, but only the researchers will be able to listen to the tapes with your permission.

If you are willing to take part in this project, we will ask you to provide verbal consent prior to the commencement of the interview. The survey will request that you tick a consent box prior to answering the questions.

### **5. Can I withdraw from the project?**

You may change your mind and withdraw from the project at any time without giving a reason. You can stop the interview at any point, please just tell the researcher and they will stop immediately.

Your decision will not affect any treatment or care you receive, or your family's relationship with The Royal Children's Hospital.

### **6. What are the possible benefits for me and other people in the future?**

There are no direct benefits for you and your child if you decide to participate.

By taking part in this project, you will be providing important information about your experiences and thoughts on your journey of care with your child, so far. This information will help shape the psychological component of the CPRS in the form of service provision. This will not only affect children treated for colorectal conditions at the RCH but can inform national and international practice. It will also aim to improve parental experience at key stages of their child's care.

### **7. What are the possible risks, discomforts and/or inconveniences?**

The survey and interview questions are not expected to be upsetting. If you become upset during the survey/interview, you are welcome to stop at any point. Furthermore, if you become upset following the interview or survey, please do not hesitate to let Dr Kim-Michelle Gilson know on [kim.gilson@rch.org.au](mailto:kim.gilson@rch.org.au). You will also be offered the opportunity to discuss your experience with the RCH CPRS Clinical Nurse Consultants, if needed. Alternatively, if you wish to talk to someone external to RCH about any distressing feelings that may arise from taking part in this study, your GP will be able to provide a referral to a psychologist within your community. There is also telephone support available through Lifeline Australia: 13 11 14 and Beyond Blue: 1300 224 636.

## 8. What will be done to make sure my information is confidential?

Any information we collect that can identify you will be treated as confidential and used only in this project unless otherwise specified. We can disclose the information only with your permission, except as required by law.

The information collected will be re-identifiable. This means that we will remove your name from the research database and give the information a unique ID number. Only the research team can match your name to your ID number, if it is necessary to do so. Research audio-files from the interview will be stored securely on a password-protected research computer in the Department of Paediatric Surgery at RCH. Once transcribed, the audio-files will be deleted.

The following people may access information collected as part of this research project:

- The project team involved with this project
- The Royal Children's Hospital Human Research Ethics Committee

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

Your data will be kept for a period of 7 years and may be kept indefinitely for research purposes in non-identifiable format.

At the end of the research project, we may present the results at conferences. We may also publish the results in medical journals. We will do this in a way that protects your child's privacy.

## 9. Will we be informed of the results when the research project is finished?

Yes, once the project has been completed, a brief summary of the group findings will be sent to you in the post.

Should you require any further information about the project, or have any concerns, please do not hesitate to contact Dr Kim-Michelle Gilson on [kim.gilson@rch.org.au](mailto:kim.gilson@rch.org.au)

Yours sincerely,

Dr Kim-Michelle Gilson  
Senior Clinical Psychologist  
Colorectal and Pelvic Reconstruction Service, The Royal Children's Hospital

You can contact the Director of Research Ethics & Governance at The Royal Children's Hospital Melbourne 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.