



### **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?**

This project will include a short online survey. This will ask you some questions about your child and the different areas of your child's hospital care that a psychologist can assist in. We are interested to know how important you think these areas are for your child and family's emotional wellbeing.

The survey will take approximately 20-25 minutes to complete.

If you are willing to take part in this project, 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 survey at any point.

If you do wish to withdraw from the project, we will use any information already collected unless you tell us not to. 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 what psychological support is needed for children, adolescents and their families. 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 questions are not expected to be upsetting. If you become upset during the survey, you are welcome to stop at any point. Furthermore, if you become upset following the 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?**

Your participation will be anonymous in the survey. This means that we do not collect any data that can identify your responses. The anonymous information we collect will be treated as confidential and used only in this project unless otherwise specified.

Any information we collect that can identify you will be treated as confidential and used only in this project unless otherwise specified. For example, we use your date of birth to allow us to calculate the ages of participants and to compare the experience and views of families who would have received diagnosis or treatment at different times (such as in the 2010s versus 2020s). If you contact us to ask that the data you provided be withdrawn (i.e., not used), we would ask for your date of birth to try to identify and remove your survey data accordingly. We can disclose the information only with your permission, except as required by law.

Anonymous research data from the survey will be stored securely in a password protected online database (REDCap). REDCap is hosted by the Murdoch Children's Research Institute, a partner with The Royal Children's Hospital at the Melbourne Children's Campus – the researchers work across both places. REDCap has numerous features to ensure that only appropriate users are able to access a project database and to restrict access to specific information within the database.

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

If you give your permission, we may store your child's anonymous (deidentified) data for an indefinite period. We would like to use these data in future ethically approved research. We will not contact you or your child to use the data in future research. Please tick the appropriate box in the survey to let us know if you consent to this.

At the end of the research project, we may present the results at conferences. We may also publish the results in medical journals.

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

At the end of the project we will send you a final letter if you request one. This letter will explain what we found out in this project – in other words, our project results. The letter will not have any information specifically about your child. You can request this summary of results letter by selecting the appropriate box in the survey.

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.