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VICTORIAN ADOLESCENT & YOUNG ADULT CANCER SERVICE

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
FOR QUESTIONNAIRE/INTERVIEW-BASED RESEARCH

HREC Project Number:	29065A
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Research Project Title:	Parent's experiences and perceptions of health service delivery within an educational setting for adolescents with chronic disease.
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Dear Parent

We are conducting a study to understand the experience of parents with an adolescent child with cystic fibrosis, anorexia nervosa or cancer (leukaemia or sarcoma). In particular, we want to understand how parents access support services for their son or daughter and themselves, especially through the school system. There has been little previous research in the area of education and medical interaction for adolescents with a chronic health condition.

We are inviting you to take part in this study and this letter tells you what the study is all about. Before you decide to take part in the study we want you to have all the facts. Please read this letter carefully and discuss any questions you have with a member of the research team.

Who is conducting the study?

The study is being conducted with the assistance of the Centre for Adolescent Health at The Royal Children's Hospital, the onTrac@PeterMac Adolescent and Young Adult Cancer Service at Peter MacCallum Cancer Centre, and The University of Melbourne.

The study has been approved by the Research Ethics Committees of the participating institutions in accordance with the guidelines of the National Health and Medical Research Council of Australia. The study is being conducted as a part of Eve Bowtell's PhD studies. Eve Bowtell is an experienced teacher and psychologist.

Why do you want me to take part?

We are asking you to take part because you have an adolescent son or daughter with a chronic health condition. If you participate you will be contributing to a greater understanding of the needs of parents and chronically ill adolescents who are attempting to complete secondary education in Victoria. It is anticipated that this information will be used by both educational and medical services in the design of support services for chronically ill adolescents and their parents.

What will being in the study mean for me?

We'd like you to take part in an interview at a venue of your choice. This will take approx 60 minutes and will be audio recorded. **The recording will be transcribed by a qualified medical transcriber. The transcriber will not be able to identify you.** You will receive a copy of the transcript of the interview.

The interview will ask questions about your experiences and perceptions of the supports that have been required during your son/daughters education and how his/her illness has impacted on his/her education. For example; how has your son/daughters' school been able to cater for his/her medical and educational needs? The interview will be broad as many aspects of health and education will be covered.

There will be no direct benefit to you from taking part in the study; however the results of the study are likely to help people who have a chronic health condition and other diseases in the future.

There will be no cost to you and if you do not want to take part this will not affect the future medical care of your son or daughter in any way. You will also be free to withdraw from the study at any stage if you no longer wish to continue.

Are there any risks if I participate?

We do not expect there to be any risk to you if you take part in this study. We have done our best to make sure that the questions do not cause you any distress.

Sometimes talking about your son/daughter's illness and your perceptions and experiences can raise emotions. Discussing your son/daughters supports at school may also raise concerns that you may have about your child's ability to complete his/her education at this time. We can provide you with further information on support services that may assist you in caring for your son/daughter and guidance in the supports available to your son/daughter for their education.

However, if you do become upset or unhappy by anything during the interview, and would like to talk to someone, we can provide you with a list of agencies who can offer some support.

How is my privacy protected?

We will make every effort to protect your privacy.

- All your information will be stored securely in such a way that it cannot immediately be identified. It will be labelled with a unique barcode number to protect your privacy. The information you provide will be stored at the Royal Children's Hospital for seven years after the end of the study at which point it will be destroyed.
- Any identifying information (your full name, address etc) will be stored separately from the information you provide. Access to this identifying information is restricted to a small number of senior members of the study team.
- Any information collected in connection with the project and that can identify you will remain confidential. It will only be used for the purpose of this research study. It will only be disclosed with your permission, except as required by law. Only the researchers and the Research Ethics Committees can access your information.
- You have the right to access and request correction of your information in accordance with the Freedom of Information Act 1982 (VIC).
- The information collected will be published as a PhD thesis, in journal articles and presented at conferences. The results will not identify you in any way.

Will I find out the results of the research?

We expect that the results of research will be published over the next few years. At the end of the project we will send you a summary of the results. This will be the whole group of participants, not your individual results.

Can I withdraw from the study?

You do not have to take part in this project if you do not want to. If you do take part you may withdraw from the study at any time and this will in no way affect your son/daughter's medical treatment in the future. Just contact us and let us know that you do not want us to use your information.

Yours sincerely

Professor Susan Sawyer: Director The Centre of Adolescent Health Royal Children's Hospital

Dr Rosalie Aroni: Senior Lecturer, Monash Institute of Health Services, Faculty of Medicine.

Dr Julie Green: Deputy Director and head of research, The Royal Children's Hospital Education Institute.

Mrs Eve Bowtell: student researcher

What if I have more questions or a complaint about the study?

If you have any questions about the study, please call-

Evelyn Bowtell (researcher) (03)93456457 or email e.bowtell@pgrad.unimelb.edu.au

If you have a complaint or would like to speak to someone who is not involved in the study, you can contact:

- The Executive Officer, Human Research Ethics, The University of Melbourne on (03) 8344 2073
- Head of Department, Ethics and Research Department, Human Research Ethics The Royal Children's Hospital on (03) 9345 5044
- Ethics Coordinator, The Peter MacCallum Cancer Centre on (03) 9656 3771

Return documents to:

**Mrs Evelyn Bowtell
The Royal Children's Hospital
Centre for Adolescent Health
2 Gatehouse Street
PARKVILLE, 3052**



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CONSENT FORM FOR PARTICIPANT TO GIVE INFORMED CONSENT TO TAKE PART IN A RESEARCH PROJECT

HREC Project Number:	29065A
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Research Project Title:	Parent's experiences and perceptions of health service delivery within an educational setting for adolescents with chronic disease.
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I (Participant name)	
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voluntarily consent to take part in the above research project
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- I believe I understand the purpose, extent and possible effects of my involvement in this project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Participant Information Statement and Consent Form.

Participant Signature		Date	
Participant Signature		Date	

I have supplied an Information Statement and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this project.

Researcher Signature		Date	
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Note: All parties signing the Consent Form must date their own signature



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VICTORIAN ADOLESCENT & YOUNG ADULT CANCER SERVICE

CONSENT FORM FOR CHILD OF PARTICIPANT TO GIVE INFORMED CONSENT TO TAKE PART IN A RESEARCH PROJECT

HREC Project Number:	29065A
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Research Project Title:	Parent's experiences and perceptions of health service delivery within an educational setting for adolescents with chronic disease.
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I (son/daughter of participant name)	
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voluntarily consent to my parents' participation in the above research project

- I believe I understand the purpose, extent and possible effects of my parents' involvement in this project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).
- I understand I will receive a copy of this Participant Information Statement and Consent Form.

Son/daughter of Participant Signature		Date	
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I have supplied an Information Statement and Consent Form to the son/daughter of the participant who has signed above, and believe that they understand the purpose, extent and possible effects of their involvement in this project.

Researcher Signature		Date	
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Note: All parties signing the Consent Form must date their own signature