



PARTICIPANT INFORMATION SHEET FOR PARENTS

Educational needs of children and adolescents with serious illness

A/Prof Claire Wakefield - Program leader, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital; Senior research fellow, School of Women's and Children's Health, UNSW

Professor Glenn Marshall – Cancer specialist; Director, Kids Cancer Centre, Sydney Children's Hospital; Conjoint Professor, School of Women's and Children's Health, UNSW

Alistair Lum – PhD Candidate, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital; School of Women's and Children's Health, UNSW (Supervised by Claire Wakefield, Glenn Marshall and Barb Donnan)

Barb Donnan – Educational Psychologist, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital; School of Women's and Children's Health, UNSW

Tracey Webster – National Learning Program Manager, Ronald McDonald House Charities

Emma Doolan – Statistician/Research Officer, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital

Mary Burns - Research Officer, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital

Dr Joanna Fardell – Post-Doctoral Research Fellow, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital

Lucy Gan – Independent Learning Project Student, UNSW Medicine, Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital

Professor Adam Jaffe – Respiratory disease specialist; Head of Discipline, Paediatrics & John Beveridge Chair of Paediatrics; Professor, School of Women's and Children's Health, UNSW

Dr Nadine Kasparian – NHMRC Fellow / Senior Lecturer, Discipline of Paediatrics, School of Women's & Children's Health, UNSW

Dr Sean Kennedy – Kidney disease specialist; Senior Lecturer, School of Women's and Children's Health, UNSW

Dr Stephen Leach - Research Fellow, School of Women's & Children's Health in the Faculty of Medicine, UNSW

Dr Daniel (Avi) Lemberg - Head of Paediatric Gastroenterology. Sydney Children's Hospital

We would like you to consider consenting for your child to participate in a research project that will be conducted by the Behavioural Sciences Unit, Kids Cancer Centre at Sydney Children's Hospital in conjunction with the University of New South Wales and Ronald McDonald House Charities.

Introduction

This research project is called "Educational needs of children and adolescents with serious illness". Your child has been invited because they are currently or were recently attending school in Australia.

This Participant Information Sheet tells you about the research project. It explains the processes involved in your child's participation. Knowing what is involved will help you decide if you consent to your child participating in the research.

Purpose of this research project

The purpose of this research is to investigate the impact of serious illness on students' educational needs.

By collecting information about student and parental educational experiences, health and wellbeing we are aiming to:

- Examine the impact of serious illness on students' educational experiences and outcomes, as well as psychosocial functioning;
- Compare the different effects of six different serious illnesses on students' educational experiences and outcomes and psychosocial functioning;
- Investigate any barriers preventing students with serious illness from having the same educational experiences as students without serious illness;

- Investigate school factors that promote wellbeing in students with and without serious illness.

It is anticipated that findings from this research will inform the development of programs and strategies to improve the wellbeing of students with and without serious illness.

Is my child eligible to participate?

Your child is eligible to participate if they are

- Currently attending a primary school, or high school in Australia OR have graduated/discontinued school in the last 5 years; and
- Currently aged between 8 and 25 years old.

As a parent you know your child best – please only invite your child to participate if you believe they are capable of completing a survey. The current study is focusing on the six illnesses mentioned above. At the moment, investigation of other serious illnesses will not be taking place.

Study procedures and risks

If your child decides to participate, they will be asked to complete an online or paper survey that will ask about their health and wellbeing and some educational experiences. This survey should take your child no longer than 15 minutes to complete.

Your child will have the opportunity to register their interest in further participation by telephone interview. If they wish to register their interest they will be required to enter their personal details, including their first name and telephone number. By responding to the question regarding telephone interviews with these details your child will be consenting to being contacted for, and participating in, an audio-recorded telephone interview. Prior to contacting your child to participate in this audio-recording a researcher will contact you to obtain consent for their participation.

The audio-recordings of these interviews will be stored on a password-protected file on a secure computer. The recordings will be transcribed and analysed to gain a richer understanding of your child's educational experiences. Your child will also have the opportunity to complete one of the questionnaires again, taking approximately 5 minutes. More details about the telephone interview and questionnaire are provided in the survey.

Are there any risks?

The questions in the survey are not designed to cause distress or discomfort. However, some distress or discomfort may occur when recalling personal experiences. Contact details of relevant services are listed below should your child require them. These details will also be provided at the end of the survey.

Completion of this survey is voluntary and your child will be free to withdraw from the study at any time without affecting their relationship with the researcher/s or hospital now or in the future.

Will my child benefit?

By completing the survey your child will have the chance to express their experiences of going to school in Australia and to assist in efforts aimed to improve the wellbeing of students in Australian schools.

Your child will also have the opportunity to WIN a \$250 VISA gift-card! The randomised draw to determine five winners of one \$250 VISA gift-card each will take place toward the end of the year 2016.

Confidentiality and disclosure of information

What you need to know about the information your child is providing.

- Any information that is obtained in connection with this study and that can be identified with your child will remain confidential and will be disclosed only with your own and your child's permission, except as required by law;
- Any identifiable information will be stored separately from non-identifiable information in a password-protected file;
- In any publication or presentation, information will be presented in such a way that your child cannot be identified;
- The results of this study are planned to be disseminated via publication in peer-reviewed scientific journals, in a co-investigator's PhD thesis, as presentation slides at scientific meetings and as summarized reports for partnering National Associations and RMHC; and

- All information given will be stored for a minimum of 15 years and 5 years after the final publication arising from this research. After this time, all data will be destroyed by complete deletion of the file from the computers and networks on which they are stored.

Complaints

This project has been approved by Sydney Children's Hospitals Network Human Research Ethics Committee (HREC approval number: HREC.14.SCHN.428). If you have any concerns about the conduct of this study, please do not hesitate to contact Alistair Lum (see contact information below) or the Executive Officer of the Ethics Committee (02 9845 3066) and quote approval number

Feedback to participants

The results of this research will be made available to participants from Ronald McDonald House Charities website and/or newsletter.

Your consent

Please be aware that

- Your decision whether or not to give consent for your child to participate will not affect your or your child's future relations with the Sydney Children's Hospital, the University of New South Wales or Ronald McDonald House Charities;
- All participation is voluntary;
- If your child consents and chooses to participate, they will be free to withdraw from the study at any time;
- By inviting your child to participate and introducing them to the online survey you are consenting to their participation in this research project.

For **further information** please contact:

Alistair Lum

Phone: Monday, Wednesday and Thursday – (02) 9385 9870

Email: a.lum@student.unsw.edu.au

Mary Burns

Phone: Tuesday and Friday - (02) 9385 2551

Email: m.burns@unsw.edu.au