



May 2011

Explanatory Statement

Parents of a child with cleft lip and/or palate

“Cleft Palate Speech Impairments in Children: Family Perceptions and Experiences”

This information sheet is for you to keep.

My name is Rebecca Robinson and I am conducting a research project with Dr Emma Bruce and Dr Charles Livingstone from the Department of Health Social Science, Monash University. This research contributes towards a Bachelor of Health Science (Honours) degree at Monash University. This means I will be writing a thesis for the completion of this degree.

You are invited to participate because of your experience of living with a child who has a cleft lip and/or palate (CLP) speech impairment. Your unique experience is important to fully understanding the impact of living with a child that has CLP.

The aim of this study is to explore and understand parents' and sibling's perceptions and experiences of the impact of the child's speech impairment on family life.

This research will contribute to the evidence base about how families adjust to living with a child that has CLP and how this may impact the sibling's. This has the potential to better inform health care services and providers in relation to the health and well-being of CLP family members.

The study involves interviews with parents currently living with a child aged 4-7 years-of-age who has cleft lip and/or palate. These interviews will be audio recorded and can be completed in person at Monash University or in a convenient location for those wanting to participate. It is expected the interview will take no more than 1 hour.

It is not anticipated that you will experience risks beyond the inconvenience of loss of time which is associated with participating in this study; however if you do experience discomfort or become distressed at any point during the interview you may withdraw from the interview immediately.

Participation in this study is voluntary and you are under no obligation to provide your consent. However, if you do consent to participate, you may withdraw up to 1 month after having approved the interview transcript and/or summary. Following this time it will be impossible for the researchers to identify your responses and remove them from the study.

Your details will remain anonymous and your privacy will be protected in line with Federal and State privacy laws. All possible measure to preserve your privacy will be taken; this includes measures such as reporting aggregate data and using pseudonyms. Your details will not be disclosed to any third parties. Please keep in mind that it is sometimes impossible to make an absolute guarantee of confidentiality/anonymity.

Storage of the data collected will adhere to the University regulations and kept on University premises in a locked cupboard/filing cabinet for 5 years. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report. After this time all records will be disposed of using shredders and a secure document bin, all electronic files will be magnetically erased.

If you would like further information concerning this study or to be involved, please contact Rebecca Robinson via email rlob3@student.monash.edu or on (03) 9928 8271.

If you would like to be informed of the aggregate research finding, please contact Rebecca Robinson via email rlob3@student.monash.edu The findings are accessible for up to 12 months.

<p>If you would like to contact the researchers about any aspect of this study, please contact either Chief Investigator:</p>	<p>If you have a complaint concerning the manner in which this research <2011000722> is being conducted, please contact:</p>
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Thank you

Rebecca Robinson