



Dear Parents

My name is Joy and I work at Temple Street University Children's hospital as the Clinical Tutor for the Royal College of Surgeons in Ireland. I am a qualified medical doctor and am involved in teaching medical students.

I would like to ask your child to take part in my research project which is a Multimedia Quality of Life Questionnaire for children with hydrocephalus attending the Neurosurgical Clinic.

Please take 10 minutes to read the information and talk to each other about it. If you would like to take part in the study please fill out the forms return them to me.

If you do want to take part - don't worry just throw everything into the recycle bin!


This study is being conducted as part of a course I am attend an MSc in Paediatrics and Child Health in Imperial College London. My research supervisor, Mr John Caird can be contacted at 01-8784200.

If you would like any more information, or would like to talk to me about this research please email me at joyewenntan@rcsi.ie I would be happy to answer any questions you may have.

Thanks for reading this letter

Joy Tan

Appendix 1. General information Sheet

 <p>Parent's Information Leaflet</p>	<p>What will happen to my child if I agree to take part?</p> <p>Your child will be asked to fill in the questionnaire on a computer or on a sheet of paper.</p> <p>Your child might require filling in the questionnaire again in the near future, which will be coordinated during your next outpatient visit for your travel convenience.</p>
<p>Study title:</p> <p>Multimedia Quality of Life Questionnaire</p>	<p>What are the benefits?</p> <p>The main aim of the study is to test if the multimedia questionnaire can record the quality of life among children with hydrocephalus.</p> <p>This questionnaire will look into the main domains of health: physical, mental, social and cognitive.</p>
<p>Why is this study being done?</p> <p>To find a quick & reliable way to measure Quality of Life among children with hydrocephalus (build-up of fluid in the brain) from the child's own perspective. The information from the questionnaire type of questionnaire can be helpful xxxxxx</p>	<p>What if my child gets upset or finds difficult to complete?</p> <p>There will be no obligation to carry on the questionnaire. You don't have to give us a reason.</p>
<p>Why is my child being asked to take part?</p> <p>I hope to invite all children aged 8 – 16 yers with hydrocephalus to take part.</p>	<p>Is the study confidential?</p> <p>This study is to be kept confidential, your child's name will not be linked to their completed questionnaire.</p>
<p>How will the study be carried out?</p> <p>This study will be conducted while your child is waiting to the doctor in the outpatient waiting area.</p> <p>It will take around 5-10 minutes.</p>	<p>Where can I get further information?</p> <p>If you need any further information now or at any time in the future, please contact:</p> <p>Principal investigator's name: Dr Joy Tan Email : joyewenntan@rcsi.ie</p>

Appendix 2. Parents information Sheet



Young People Information Leaflet

Study title:
Multimedia Quality of Life Questionnaire

Why is this study being done?

To test a quick and easy questionnaire done on a tablet or computer.

Why am I being asked to take part?

To test if children and young people find this multimedia questionnaire easy to use

How will the study be carried out?

This study will be done while you are waiting for the doctor

It will take around 5-10 minutes.

What will happen I agree to take part?

You will be asked few questions either on a tablet or on a sheet of paper.

You might need to fill in again the next time you visit for clinic.

What are the benefits?

If this works I will be able to ask other children questions using this type of questionnaire.

What if you get upset or find it difficult to complete?

You can stop whenever you like, you don't have to give us a reason .

Will people know my answers.

Your name will not be part of the questionnaire

Where can I get further information?

If you want to know more, please contact me

Principal investigator's name:

Dr Joy Tan

Email : joyewenntan@rcsi.ie

Appendix 3. Young people information sheet