PARTICIPATION INFORMATION SHEET – For parent/caregivers  
Quantification of oculomotor deficits

Who are we?
We are a group of researchers and clinicians interested in how eyes move. Our goal is to make these measurements more accurate in the future. We come from a variety of backgrounds including vision science, psychology, optometry and ophthalmology.

Principal Investigators
Steven Dakin (Head of School, Optometry and Vision Science)
Shuan Dai (Honorary Academic, Ophthalmology, School of Medicine, Faculty of Health Sciences, University of Auckland)

Co-Investigators
Peter Bex (Professor, Psychology, Northwestern University, USA)
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Why are we asking you for your help?
We are developing a system to accurately measure alignment of the eyes in children and adults. We need volunteers to undergo the new test. This document provides information to help you decide whether this project is something you and your child would like to be a part of.

How do you know if you will be eligible?
We need children (6-15 years) with:
1. Stable and long-standing strabismus (eyes not looking the same direction/squint/lazy eye/eye turn).
2. No strabismus (normal vision).

If your child has been referred to the study by their eye care professional, we can check your child’s eligibility for you if you like. If you have come across this study another way, we will do some screening clinical tests to determine whether your child is eligible for the study.

What should you expect?
We are comparing a new method of assessing alignment of the eyes to some existing tests. If your child is currently under the care of an eye care professional, he/she may have undergone many of the standard clinical tests. If so, we will be able to assess your child’s eligibility through their clinical record (if you tick the box saying this is ok). If your child is not under the care of an eye care professional, and/or you would prefer not to share your child’s clinical records with us, we will need to do some standard clinical tests for screening.

The study will take place at the Grafton Campus of the University of Auckland. Your child’s first visit will take 1-2 hours, depending on how many standard clinical tests we need to do. After the standard clinical tests, we will use a new test to measure your child’s eye alignment and how your child uses his/her eyes together. During these new tests, your child will look at a computer screen while their eyes are being tracked and video recorded. These tests require that the eyes see different content, so your child will wear goggles during testing. We will ask your child to look at dots and shapes on a display, and in some cases, ask him/her to answer questions about them.

We will ask you and your child to come back for a second re-test visit about 6-8 weeks after the first visit. This second visit will take about 45 minutes to an hour. We will repeat some of the standard clinical tests, as well as the new measures of your child’s eye alignment and binocular function.
Risks/Benefits:
There are no known risks associated with testing. Boredom during testing is possible. It is also possible the goggles may cause mild discomfort. We will offer breaks as needed if this occurs, and you or your child can stop testing at any time if you wish. There are no direct benefits for you child. However, participation in this study will help us to better understand how eye position can be accurately measured, which could lead to substantial benefits for those who need surgery to align their eyes.

Costs
We can reimburse your travel costs (in the form of a $20 petrol voucher per visit), and we can provide your child with coloured pencils to express our appreciation.

Data storage/retention/destruction/future use
All data collected as part of this study will be backed up and stored securely on a server. Paper records will be stored in locked filing cabinets and electronic data will be stored in password protected computers, accessible only by the named investigators. The data will be stored for 6 years and then destroyed using appropriate confidential document destruction services.

Confidentiality
Only the named investigators will have access to clinical, eye tracking, and video data. At the end of the study we hope to publish our findings in a scientific journal. This will be done in a way that does not identify you. The only exception is use of videos or images. Sometimes videos including eye movements are helpful in communicating information in presentations or publications of the findings. Videos could identify your child. If you are ok with us using video or images of your child please tick the box indicating this on your consent form. **Unless you tick this box, we will not use any images or video of your child when presenting our findings.**

Participation is your choice
Please take your time to read this document and to decide whether you and your child wish to take part, and feel free to discuss your decision with whānau, family or significant other support people. Taking part is completely voluntary (your choice); we need to make sure that you and your child are happy to participate before we start. Please note that if you or your child are currently under the care of an eye care professional, your decision to participate in this study, or not, will have no impact on your clinical care. Your participation, or not, will likewise have no bearing on your or your child’s relationship with the University of Auckland or your eye care professional.

Right to withdraw
If you and your child do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. You also have the right to withdraw any data collected as part of the study from the time of your participation up to six months after data collection.

What information will you receive?
Although it is unlikely, if the new tests provide different information about your child’s eye health, we will inform you of this, and make appropriate referrals if necessary. If you would like a summary of the project findings, please indicate this on the consent form. Note that there is often quite a delay between when the data is collected and when a paper is published, so there may be a gap in time between when you participate and when you receive the summary.

If you decide to participate or have further questions, please contact Tina Gao directly (t.gao@auckland.ac.nz).
Thank you so much for your time.

Tina Gao (Project coordinator)

Approved by the Auckland Health Research Ethics Committee on 8 December 2017 for 3 years, reference number 000002.
For any queries regarding ethical concerns you may contact the Chair, The Auckland Health Research Ethics Committee, The University of Auckland, Research Office, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: ro-ethics@auckland.ac.nz. If you require Māori cultural support talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324. If you have any questions or complaints about the study you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 ext 3204. Also, feel free to use the email hkwresearch@waitematadhb.govt.nz with any questions or concerns.