

KIDSKIN FOLLOW-UP STUDY

INFORMATION FOR PARTICIPANTS

You are part of a unique group of people who's childhood sun exposure behaviours and time spent outdoors was closely monitored. This information provides an opportunity to now undertake a further study to compare this data with outcomes obtained from the group who are now early adults. We are asking you to take part in this study.

We aim to assess myopia or short-sightedness rates in approximately 900 of 1776 original young adult participants, who were part of the Western Australian Kidskin Study while they were in primary school in the 1990s. The Kidskin Study intervention resulted in a reduction in time spent outdoors and an increase in the use of sun protection while outdoors. We wish to now investigate the possible impact that this intervention has had on the development of myopia in these participants who are now young adults.

To gather the data, we would like to repeat some of the questions and measures that we performed in the original Kidskin Study. This includes completing a questionnaire, undertaking a comprehensive eye examination, have naevi counts, and we will also ask if you would provide a blood sample.

WHAT WE WILL ASK YOU TO DO.

We are asking you to come to the LEI, located on the site of Charles Gairdner Hospital to do the assessment. We have included a map and information on how to get there, and where to park. We have evening and weekend appointments as we can use the facilities outside of normal clinic hours. The total time for the assessment is about 2 to 2.5 hours. We will have refreshments available during this time.

We are asking you to please complete the enclosed questionnaire about your general and eye health, educational outcomes and sun-exposure behaviour. This can be done at home, online or during the assessment at LEI.

When you arrive at LEI the Study Team can answer any questions you may have and will ask you to please complete the consent form. We will then measure height, weight, skin folds, assess skin wrinkling, take your blood pressure, take digital photographs of your back to assess naevi counts, and count the naevi on your right arm. These naevi counts will be compared with the baseline data we obtained from you in the original Kidskin Study. **You don't have to participate in tests you don't feel comfortable with.**

The main part of the follow-up involves having an eye assessment.

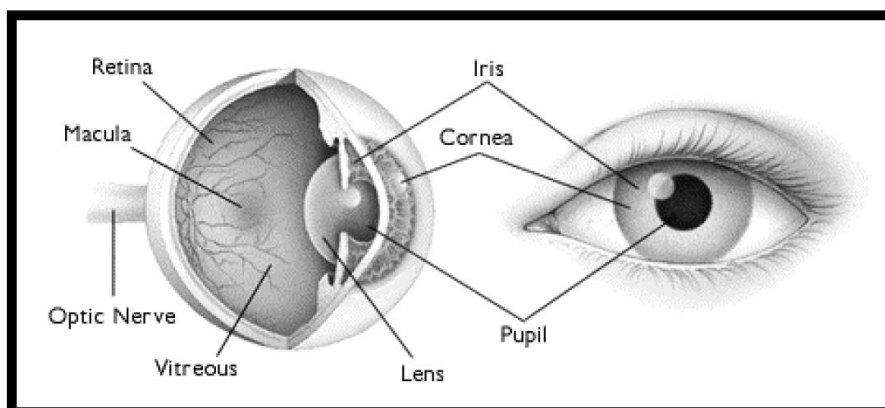
THE EYE ASSESSMENT

We will ask you to do eight different eye tests. Again you can choose if you don't want to do all of them. The eye tests will be set up in a series of rooms at LEI, and a Study Assistant will accompany you from room to room. The tests will be done by ophthalmologists (eye specialists), orthoptists and ophthalmic research assistants.

For all of these tests you will be seated on a chair, and either the examiner or camera/machine will come closer to your eyes. The sights tests are the following

- Visual acuity: you will be asked to read the letters on an eye chart.
- Short or longsighted: an automatic machine will determine this and whether you require glasses.
- Eye movements: you will be asked to focus on a near target and then cover each of your eyes alternately while you look at the target. The test is then repeated up close. This will determine if the eyes are straight or if an 'eye turn' is present. You then follow a pen-light with your eyes, but they keep your head still. This will identify under/over action of eye muscles.
- Stereopsis: using a 3D card we assess your depth perception, or seeing things in three dimensions.
- Ocular dominance: we can see if you use one eye more than the other one.
- Ultra violet (UV) photography: we will take photographs of your eye to see if there is any UV damage to the front of the eye. You need to look at a light so the eyes are still and then the photographer will take photographs. While the photographer is taking the pictures, you will see a series of bright flashes. You may experience an after-image which is a normal phenomenon.
- Eye colour and eyelid position photos: taking photos for the eye colour and shape of the eyelids.
- Axial length: an ultrasound machine, that does not touch your eye, will measure the length of your eye – from back to the front. You will need to look at a light so your eyes are still.
- Central corneal thickness (CCT): you will be asked to look at a picture in a machine and the machine will measure the thickness of the cornea.
- Intra ocular pressure (IOP): we will measure the pressure of the fluid in the eye. This machine has a tiny probe that gently touches the front of the eye but you are hardly aware of it. You will also be given anaesthetic drops that wear off after 3-5 minutes.
- Photograph and scan of retina, optic nerve and vessels at the back of the eye: this involves dilating your pupils. The ophthalmologist will put dilating eyedrops in your eyes. This will enlarge your pupils. The drops take about 15 to 20 minutes to dilate your pupils. A specialised machine and camera will then take photographs and scan or the back of your eyes. This does not hurt, or touch your eyes, but the machine makes a series of white flashes.
- Your eyes will stay dilated for 1 to 2 hours, you might be sensitive to bright light. You will however, be OK to drive.

At the end of the examination your results will be discussed and you will be provided with an eye report, and whether you might need glasses (if you don't already have them).



BLOOD SAMPLE

We are asking if you could please provide a blood sample. The sample will be used to assess your Vitamin D levels (serum 25(OH)D₃). If any of your results are outside the normal range we will recommend that you see your GP.

We will ask your permission to obtain DNA from your blood or saliva sample to use for DNA analysis of genetic analysis of risk factors associated with the development of childhood and adult health and disease.

We are also asking everyone for permission to extract DNA from this blood sample to look specifically at 'epigenetics' which looks at how external factors might influence the 'packaging' of DNA. Genetics refers to the gene sequence, or the DNA. Epigenetics refers to all the other factors that control how and when each gene in the DNA is expressed or 'turned on'. To explain the difference between genetics and epigenetics consider that "your body is your DNA and your clothes (epigenetic modifications) effect how much of your body can be seen". There are many factors which influence the clothes your wear. Similarly, there are many environmental factors which influence epigenetic packaging of your DNA. It is thought that factors like diet and diseases can change the 'packaging' of DNA (not DNA itself), which makes DNA more vulnerable to be affected by factors in the environment (diet, smoking, disease etc).

EDUCATIONAL DATA

We are starting to see a link between time spent outdoors and myopia. It is considered that those who spend hours indoors studying may have higher levels of myopia. A section of the Questionnaire you will be asked to complete, contains questions on your educational outcomes. With your permission, we would also like to get access to your National Assessment Program Literacy and Numeracy (NAPLAN) scores from Australian Curriculum, Assessment and Reporting Authority (ACARA). This information will provide us with a measure of the time spent indoors studying.

SIDE EFFECTS OR RISKS

- The photograph of the eye may cause slight blurred vision from a bright flash for a brief period
- Dilating drops may cause blurred vision and light sensitivity. This can last 1-2 hours. We also will ask you to wait for a short while if you are driving home.

- Having a blood sample taken, or the thought of a needle may cause you to feel faint. You will be seated for this procedure to prevent you falling, but please tell the Doctor if you are not feeling well. Also, you may feel discomfort, local irritation, pain, bruising or infection as a result of having a blood sample taken.
- When having your blood pressure taken, you may experience slight pressure caused by the inflation of the cuff. This will ease when the test is complete.

CONFIDENTIALITY

All information we collect is strictly confidential.

CONSENT

We will be asking for your signed consent to participate in this Kidskin Follow-up Study. You are free to withdraw from any part of the assessment at any stage, and you can choose not to undergo any of the measurements or tests.

QUERIES

If you have any questions please contact Professor David Mackey or the Study Team on 08 9381 0707.

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time.

In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Research Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to hreo-research@uwa.edu.au

All research participants are entitled to retain a copy of any Participant Information and/or Participant Consent Form relating to this research project.