

THE RAINE EYE STUDY



INFORMATION FOR PARTICIPANTS

The main focus of the 20/21 year follow up is on vision and eye health. We are collaborating with researchers at the Lions Eye Institute (LEI) and would like you to have an eye examination. We are trying to identify genes and events that may cause eye disease. There is also virtually no information on normal eye function in young adults, which is the time when your vision is at its best.

We would like to repeat some of the questions and measures that we have performed in the past. This is a very short questionnaire. We will also ask if you would have a DEXA scan.

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 out of normal clinic hours. The total time for the assessment is about 4 hours. We will have refreshments available during this time.

We are asking you to please complete the enclosed questionnaires. This can be done at home, and brought into the assessment at LEI.

When you arrive at LEI, we will ask you to complete the consent form and the Raine Study Staff can answer any questions you may have. During the assessment we will again measure height, weight, waist, hip, skin folds, take a photocopy of your hands to measure finger length and take your blood pressure. As previously, anything you don't feel comfortable with, you don't have to do.

The main part of the follow-up involves having an eye assessment, a DEXA scan and a liver scan (Fibroscan).

THE EYE ASSESSMENT

We will ask you to do twelve 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 the Raine Study Assistant will accompany you from room to room. The tests will be done by ophthalmologists (eye specialists).



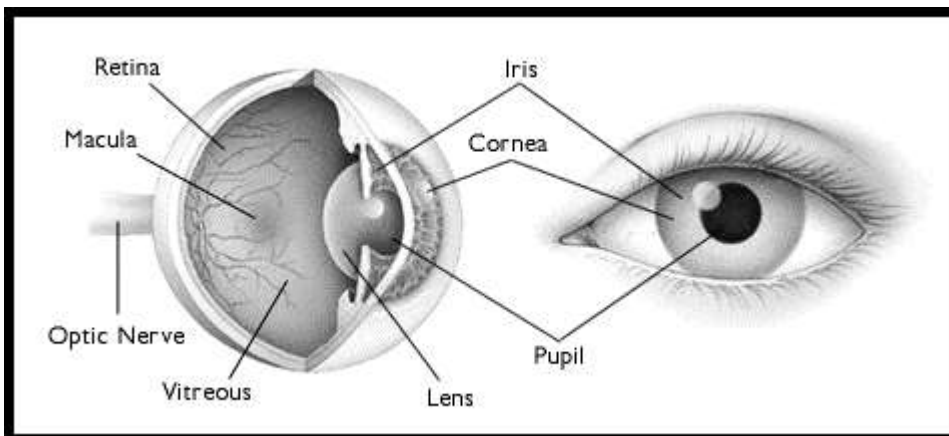
For all of these tests you will be seated on a chair, and either the examiner or camera/machine will come closer to your eyes.

The sights tests are the following

- Visual acuity: you will be asked to read the letters on an eye chart.
- Contrast sensitivity: using another eye chart we will assess your ability to see shades of gray on a white background.
- 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 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 eye colour and shape of eyelids.
- Axial Length: an ultrasound machine, that does not touch your eye, will measure the length of your eye - from the back to the front. You will need to look at a light so your eyes are still.
- Central corneal thickness (CCT) You will 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.
- 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 15 to 20 minutes to dilate your pupils. A specialised machine and camera will then take photographs and scan of the back of your eyes. This does not hurt, or touch your eyes, but the machine will make a series of white flashes.
- Your eyes will stay dilated for 1 to 2 hours, you might be sensitive to bright light and your vision might be slightly blurred. We recommend that you don't drive and get a lift or take public transport. Please contact us if this is a problem.

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



Side effects or risks

- The photograph of the eyes 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 recommend that you don't drive home.

DEXA Scan -As part of the assessment we are asking you to have a body composition scan using a DEXA machine. DEXA stands for Dual Energy X-ray Absorptiometry and it is the most commonly used test for measuring bone mineral density. This involves lying still on a bed and a scanner will capture information on bone density, fat and muscle distribution (picture below). The procedure is non-invasive and takes 6 minutes. The radiation involved is much less than an X-ray. You will receive approximately 0.8 microSieverts from the total body composition scan. To provide a comparison with other radiation sources an airline flight from Darwin to Perth results in exposure to 16 microSieverts and a normal chest x-ray exposes you to approximately 40 microSieverts. Anyone who was pregnant or thought they might be pregnant would not be scanned. We will give you a body composition report from the scan. The DEXA scanner (and the Fibroscan) is in the hospital building next to the Lions Eye Institute. The Raine Study RA will walk you across to the scanners and then back.

DEXA Scanner



FIBROSCAN

In the 16/17 year follow up you may have had a liver ultrasound to check for non alcoholic fatty liver disease. A Fibroscan is a very quick scan of your liver using sound waves. This scan checks the health of your liver as a whole. It only takes about 5 minutes.

BLOOD SAMPLE

As before, we are asking if you could please provide a fasting blood sample. We will make an appointment for our Raine study phlebotomist to visit you at home to take an early morning fasting blood sample. Again, we would also do the regular blood tests looking at fats, glucose, insulin, coeliac disease antibodies, iron levels. We will send you these blood test results. As the blood is batch tested, this will be two to three months after the sample was taken. If any of your results are outside the normal range we will recommend that you see your GP.

If we do not have a DNA sample from a previous follow up, 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 you wear. Similarly, there are many environmental factors which influence epigenetic packaging of your DNA.

Researchers want to examine the 'package' of DNA at a specific age - 20 to 21 years of age and to compare it to DNA from your blood collected at 5 years of age. Comparing two samples of the same DNA will enable researchers to see if there have been any changes to the DNA 'packaging' over a fifteen year period. It is thought that factors like diet and diseases can change the 'packaging' of the DNA (not the DNA itself), which makes the DNA more vulnerable to be affected by factors in the environment (diet, smoking, disease etc).

Confidentiality

All information we collect is strictly confidential.

Consent

We will be asking for your signed consent to participate in the follow-up. 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 the Raine Study on 9489 7792