

**INFORMATION FOR PARTICIPANTS  
DNA (GENETIC) TESTING & STORING**

**WHAT IS DNA?**

DNA is the chemical compound which genes are made of and is often referred to as the building blocks of life. Genes are inherited from both parents. A mix of genes may lead to a medical problem early or later in life. A gene mutation (an alteration to DNA) may be associated with a particular disease.

**HOW IS DNA OBTAINED? Where is my DNA?**

In the Raine Study DNA is obtained from a blood sample (about a teaspoonful) or from a saliva sample. Over the past years, blood and saliva have been collected from participants during the Raine Study follow ups and for many of you we already have a DNA sample. In the Raine Eye study we want to collect another DNA sample on all members of the cohort to study DNA packaging also known as epigenetics. Your DNA will be frozen in a small test-tube, labelled with a number and stored in a designated Raine Freezer. Genetic data relating to the sample is stored as a series of numbers and is encrypted by code.

**WHY IS DNA TESTED?**

Certain mixes of genes may lead to medical problems early or later in life. A gene mutation (an alteration to DNA) may be associated with a particular disease, for example by making you more susceptible to something in the environment e.g. tobacco smoke. Genetic testing helps find out about diseases and what causes them. Medical research also looks at good health, and the mix of genes and environments of people who enjoy healthy lives and who do not develop disease. DNA is long lasting and may be stored for an indefinite period of time. In the future, the DNA could be tested in ways that are currently unknown.

**INFORMED CONSENT**

DNA testing is a complex and changing area. The Raine Executive Committee (consisting of Professor Fiona Stanley, Professor John Newnham and other senior researchers) will protect your interest at all times. Any further research involving your DNA will only be conducted if we have your consent and then if the research has the approval of both The Raine Executive Committee and The University of Western Australia's Human Research Ethics Committee.

## **The Raine Study 23 Year follow up Sleep and Respiratory study**



### **WHAT IS EPIGENETICS?**

Epigenetics is the study of how DNA is packaged or wrapped. Similar to the way clothes alter how much of your body we can see; epigenetic changes alter how much of your DNA is seen in your body. In the Raine Eye followup we will be studying how your DNA packaging has changed from childhood (5 years) to adulthood (23 years) and how this influences health and disease in the Raine study.

### **RESULTS**

The Raine Study will undertake to inform you of any results where it would be beneficial to your health and wellbeing to have this information. There is the possibility that future DNA testing may result in new information about diseases or potential diseases. Some of this information will have no importance as far as your health is concerned but some may have health implications for yourself and your family.

### **HOW WILL THE RAINE STUDY USE THE DNA RESULTS?**

DNA in the Raine Study is used to look at how life events, particularly early life, interact with genes in the pathways to health and disease.

### **BENEFITS**

Participating in the Raine Study may ultimately help a better understanding of health and how to prevent and treat illness. There are no benefits or financial reward to you for donating DNA.

### **LEGAL IMPLICATIONS**

We will not let anyone know that we have your DNA sample and any identifiable results will not be made available to anyone unless disclosure is required by law.

### **WHAT IF I CHANGE MY MIND?**

You maintain the right to withdraw your consent and DNA sample at any time. If you wish to have your DNA sample withdrawn, contact the Raine Study and let us know in writing and it will then be destroyed.

### **DO YOU HAVE FURTHER QUESTIONS?**

If you have any questions about DNA testing, please contact the Raine Study Manager or the Scientific Director of the Raine Study

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