## The Raine Study Consent at eighteen years of age INFORMATION SHEET

Thank you for being part of the Raine Study. At eighteen years of age, we now need your own consent to be in the Raine Study. You have already given consent at 13 and 16, when your parents were your legal guardians, but now at 18 you have different legal rights and responsibilities.

We would like your consent for the following

1. To continue to be active in the Raine Study and for the Raine Study to contact you We will send you newsletters and information, and invite you to participate in future follow ups. You don't have to participate in follow-ups if you don't want to.

## 2. Use the data we have previously collected on you.

Over the past 18 years you and your parents have filled out questionnaires about your health, your sporting activities, your diet, school work, your mood, your height, weight, heart functioning etc. We have this data in a large anonymous database and we use it for research looking to see what factors contribute towards health and disease. At 18, we request your permission to carry on using this information.

## 3. To obtain data that might be on public databases

There is information in various places on everyone. Some of this information would increase the value of the research database on the Raine Study. Some examples of this information include: 1) WALNA test results which are the results of tests done in WA schools; 2) the WA school dental records which has information on your teeth if you ever visited a school dentist; 3) the WA Hospital Morbidity Data System which stores information if you ever were admitted into hospital; and 4) the Cancer Registry, if you were ever diagnosed with skin cancer or any form of cancer. We would like your permission to access this type of information to add it to our database. It means that we will have good information on the whole study and we don't then ask you for this information in questionnaires at follow-up.

## 4. For future DNA analysis

Previously we may have collected a blood sample and asked your parent's permission to analyse your DNA. We use DNA to look at issues of how the environment and genes interact to contribute to health and illness. We have included a separate detailed information sheet about DNA. Please read this and contact us if you have any questions.

The data collected on you as part of the Raine Study is part of the huge Raine Study Database. This data is de-identified, which means that it can't be traced back to individual people, and is stored in a separate place to your personal information. Only the Raine Study Staff have access to your personal information e.g. name, address, etc.

Please post the signed forms back to us in the reply paid envelope. Alternatively you can fax them to 9489 7700. If you can scan the consent forms, you can send them by email to <a href="maine@ichr.uwa.edu.au">raine@ichr.uwa.edu.au</a>. If we don't receive consent forms back from you, your information will remain with the rest of the Raine Study information.

If you have any questions about completing the forms, or would like further information or explanation, please don't hesitate to phone Jenny (9489 7795) or Diane (9489 7794) and we will be happy to talk to you.

Kind regards

Jenny Mountain Raine Study Manager (9489 7795)

Diane Wood Raine Study Team Leader (08 9489 7794)