



## The Raine Study Priority Setting Project -Participant Information Consent Form. (PICF)

### Researchers involved in the study.

- Associate Professor Rebecca Glauert
- Anne McKenzie AM
- Diane Wood
- Gracie Cayley

### Invitation:

You are invited to participate in The Raine Study's Priority Setting Project to create a Top Ten Priority List created by Raine Study Participants to guide the Raine Study's direction of research.

**Aim of the Study (What is the project about?)** The Raine Study and the Raine Study Community Advisory Committee (RSCAC) have initiated this priority-setting project. The aim is to

- conduct an anonymous 5 minute online survey to identify themes and topics of interest for future research considered important by all of The Raine Study's participants.
- Consult with the Priority Setting Project Steering Group to provide input.
- Hold an optional consensus workshop with The Raine Study's participants to develop the top ten priorities that will be used to inform future Raine Study research.
- Publicise the results of the priority setting results and its process and present it at The Raine Study Symposium.

### What does participation involve?

- Participating involves **completing an anonymous 5-minute survey**. You will be given the opportunity to identify yourself and **express interest in attending a consensus workshop** to discuss the overall results and create priorities at a consensus workshop on **Saturday 5th of October 2024 9:30-3:30 at UWA School of Population & Global Health, Clifton Street building Nedlands, Clifton Seminar Room 3 and 4. Lunch, Tea breaks and Parking provided and directions/ Map supplied via booking email.**

### Voluntary Participation and Withdrawal from the Study

Participating in this study is voluntary. You can withdraw from this study, at any time, regardless of whether you may have previously given consent. If you wish to discontinue with the process, you may choose what information you may have already given us at the appointment or online, that we can keep. Withdrawing your consent from taking part in the testing process will not influence our ongoing relationship with you, and you do not have to explain.

### Privacy Information - Where is your data collected and stored?

The University of Western Australia is the custodian for The Raine Study. The data is collected and managed in accordance with the University's Information Privacy Policy and Guidelines.

Data is collected and stored according to strict security, confidentiality, and governance protocols detailed in the Researcher Engagement Policy (<https://rainestudy.org.au/>), The University's Information Protection Policy, and in accordance with the legislation, codes, and guidelines detailed in the Data Confidentiality protocols. Research data will be securely stored forever (in perpetuity), given the longitudinal nature of this study.

All The Raine Study data is stored in a separate, secure, password-protected database, located and managed in The University of Western Australia's infrastructure, accessed only by The Raine Study staff. The storage and management



of identifiable data will be stored separately from the confidential questionnaires and health assessment data and managed in accordance with relevant University Policies by Raine Study staff only.



### **How will this data be used?**

This data will be used to create the Top Ten Priority List created by Raine Study Participants to guide the Raine Study's direction of research. The results will be emailed and available on the website.

### **Possible Benefits**

We want to use participant opinions and perspectives to create a Research Priority List which will be used to show researchers what topics our participants feel should focus on for the future of the Raine Study and its research. As this is a unique project, your responses will shape the future of The Raine Study's research and potentially cohort involvement approaches in health research.

**Possible Risks and Risk Management Plan** - There are no foreseeable risks in this study.

**Contacts** - If you would like to discuss any aspect of this study, please feel free to contact:

#### ***The Raine Study Follow-up Manager Diane Wood***

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#### ***The Raine Study Participant Engagement Assistant Gracie Cayley***

Email: [gracie.cayley@uwa.edu.au](mailto:gracie.cayley@uwa.edu.au)

#### ***Chief investigator Associate Professor Rebecca Glauert***

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### **Consent**

I understand that by completing the survey I consent to take part in this project and if choose to supply my details I may be contacted to ask my availability to attend the workshop. I understand that all survey results are submitted anonymously.

Approval to conduct this research has been approved 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 Ethics office at UWA at (08) 6448 3703 or by emailing [humanethics@uwa.edu.au](mailto:humanethics@uwa.edu.au). All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.