

The Raine Study Priority Setting Project Consensus Workshop - Participant Information Consent Form (PICF)

Researchers involved in the study:

Associate Professor Rebecca Glauert – Raine Study Scientific Director

Anne McKenzie AM – Consumer Involvement advocate

Diane Wood - Raine Study Participant Engagement Co-Ordinator

Gracie Cayley – Raine Study

Invitation:

You are invited to attend The Raine Study's Priority Setting Consensus Workshop to create a Top Ten Priority List created by Raine Study Participants to guide the Raine Study's direction of research. This workshop will be held on Saturday 5th October 9:00 am – 4:00 pm on the UWA campus at the School of Population and Global Health at Clifton Street campus Nedlands, in Seminar Rooms 3 and 4. Lunch, tea breaks, and parking are supplied. More details will be provided in the booking email.

How will participant be selected for the consensus workshop.

The workshop is designed to host between 20 and 30 attendees, with a maximum capacity of 30 participants. Prospective attendees will be informed that admission operates on a first-come, first-served basis. Applications will also be reviewed to strive for an even representation of genders and generations, where possible. Notification will be sent exclusively to those who successfully secure a place.

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. This Consensus Workshop is the second part of this project, in which we have asked participants to identify themes and topics of interest for future research considered important by all The Raine Study's participants. The aim of this Consensus Workshop is to:

- Hold a priority-setting 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, its process and present it at The Raine Study Symposium. Make the results available to the cohort via the websites and newsletters.

What does participation involve?

This will be a 9:00 am-4:00 pm Consensus Workshop in which you will be asked, as part of a group, to rank different areas of research identified as important by the wider Raine Study cohort. You will be asked to give your perspectives and feedback regarding the different identified areas of research. As this will be a full-day Consensus Workshop, you will be provided with lunch and receive payment for your participation.

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](#) (), 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 from this project will be published and presented at The Raine Study Symposium. The result will be supplied by email and 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

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Chief investigator Associate Professor Rebecca Glauert

Email: rebecca.glauert@uwa.edu.au

Consent

I understand that by attending The Raine Study's Priority Setting Consensus Workshop, I consent to take part in this project.

I _____ have read the Participant Information Consent form explaining the Raine Study's Priority Setting Project Raine Study -up. Any questions I have asked have been answered to my satisfaction.

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

