

Information Sheet for Parents

What is the study about?

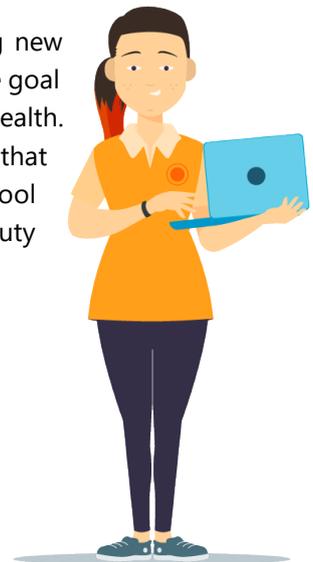
Researchers from the Black Dog Institute at the University of New South Wales are investigating mobile applications (apps) that could be used to help prevent depression in young people on a large scale. The researchers are also interested in learning more about the health, wellbeing and experiences of young people that may contribute to depression and mental health problems. This landmark study is going to involve 20,000 young people across 400 schools in NSW. Your child's school has enrolled to participate, and it is now up to you and your child to decide if your child will take part.

What are the benefits? Who can participate?

We hope that the information from the Future Proofing Study will lead to exciting new findings about the health and wellbeing of Australian young people, with the ultimate goal of helping future generations of young people to experience improved mental health. Students who take part in the study may benefit directly by receiving interventions that prevent depression. We will also identify students in need of support and let the school counsellor (or if they are not available, we'll let someone else, usually the deputy principal) know.

To take part, your child is required to:

1. Be in Year 8
2. Have their own smartphone (Android or iOS)
3. Have permission from a parent or guardian



What does it involve?

If you consent to your child taking part in this study, they will be asked to:

1. **Complete online surveys during allocated class time**, taking approx. one classroom period each time. These will be held three times in the first 12 months and then once each year until Year 12 (7-8 times in total). The surveys will cover depression, anxiety, suicide, self-harm, drug and alcohol use, traumatic experiences (e.g. accidents, violence, abuse), bullying, gender identity, puberty development, and from Year 10 onwards, sexual behaviour. A final online survey will also be sent to students one year after they complete high school. **The security of your child's information is our priority.** All data will be non-identifiable and stored securely in accordance with UNSW research ethics requirements.
2. **Use a 'Future Proofing' smartphone app.** All students will be invited to install and use a new app designed by the Black Dog Institute specifically for this study. The Future Proofing app has the capacity to collect a range of information both actively via mood ratings, logic games, and voice recordings, and passively via

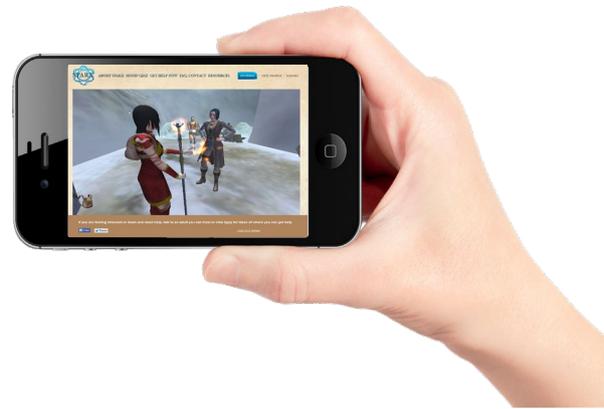


the phone's inbuilt location and movement sensors. We are collecting this information because there is evidence to suggest that things like physical activity, voice changes, sleep, and movement between locations might be early indicators of deteriorating mental health. Collecting this information will help the researchers verify whether this is the case and work out ways to detect mental health problems early. For the most part, the app will run in the background and students will only be asked to actively use it for 10 minutes at a time to complete the games and mood ratings. This will happen weekly for the first 6 weeks of the study, and then once each time they complete a study survey as described above in Step 1. Please see the **Apps Information Sheet** on [our website](#) to learn how your child's privacy will be protected within the app.

3. **Half of participating schools will be randomly assigned to use an additional app** called SPARX-FP for 6 weeks during Year 8. SPARX-FP is a game designed for teenagers where users learn about psychological strategies to manage emotions. When these students are in Year 9, they may also be invited to use another app designed to help with their sleep. Please see the **Apps Information Sheet** on [our website](#) for more details about both of these apps.

Does my child have to take part?

No. Participation in this study is entirely **voluntary**. We encourage you to discuss this study with your child. A student information sheet is provided on [our website](#) for you to download and read together. If you or your child decide to take part and later change your mind, you are free to withdraw from the study at any time, without explanation.



Are there any risks? Why might I not want my child to take part?

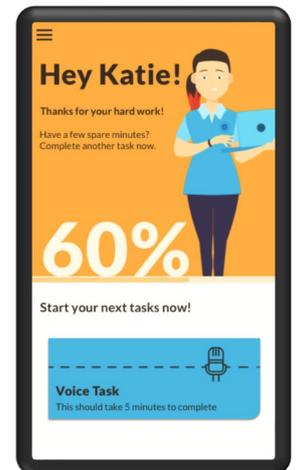
This study aims to prevent depression but should not replace any existing treatment or support your child might be receiving (medication, therapy). Your child will be provided details of support contacts throughout the study, and you will also be provided with a contact list should you require support as a parent. The study uses only a very small amount of mobile phone data. All participating students will receive a \$20 online gift voucher in the first year of the study. This covers any phone data and usage costs.

The online surveys ask about sensitive topics including suicide and traumatic experiences. If your child expresses thoughts or plans about suicide, we want to ensure they are OK. We will notify their school counsellor so they can check in with your child. If the counsellor isn't available, the deputy principal or other wellbeing staff will be informed. If your child changes schools during the course of this study, we will notify you about this information instead and provide you with details of support services in your area. When your child is in Year 12, they will be asked about sexual abuse. If your child indicates they have been abused, we are legally required to let their school know so that a report can be made to the Department of Family and Community Services. If they are no longer attending the same school as when they started the study, we will inform you instead.



What information will be collected and how will it be stored?

Information will be collected via the online surveys and the Future Proofing app. This app collects information from your child including their mood and audio recordings of their voice while they read a sample of sounds (e.g., 'Pa, Ka, Ta'). Their voice is **only** recorded when they activate and complete the inbuilt reading tasks. Their performance on two brain training games and a typing task within the app will also be recorded. Phone sensors will obtain continuous measurements of location (via GPS) and movement (via accelerometer and gyroscope sensors) for the first three months of the study, however, you can elect for location and movement information not to be collected on the online consent form. Your decision will not impact the other components of the Future Proofing Study that your child can participate in.



We would also like to request access to health and education records that are routinely collected by the Australian government (e.g. administrative records about your child's birth, healthcare, and school results). These records are **confidential** and will be accessed in a format that will not identify your child.

We want to include these records in the study to learn more about how changes to mental health affects how young people access the health system as they get older, and what influence mental health problems might have on school results. Because it is time consuming to collect this type of information using traditional methods like surveys, researchers can instead use a procedure called 'Record Linkage' which involves submitting an application directly to a specialist linkage agency (e.g. [Centre for Health Record Linkage](#), [Australian Institute of Health and Welfare](#), and [NSW Education Standards Authority](#)) to request records of interest for a particular group of research participants. Requesting this type of information involves a rigorous application process that requires researchers to justify the necessity of using this information in their research, as well as providing research ethics approval.

Record linkage is a one-way process. This means that the Future Proofing research team may receive your child's birth, health, and education records from these linkage agencies, however, they will not share information provided by your child from the study surveys or apps with these agencies or anyone else. For more details about this, please see the **Requesting Health and Education Records Information Sheet** on [our website](#).

You can choose to opt your child in or out of the record linkage aspect of the study. There is an option to indicate your choice on the online consent form. It will not impact the other components of the Future Proofing Study that your child can participate in.

All of your child's data will be stored and managed for 15 years according to the relevant privacy laws. In all cases, your child's information will be stored in a way that will not allow them to be identified.

At the end of the study, the research team would like to store your child's de-identified data in a databank called the Black Dog Institute Data Bank – Future Proofing Study. This allows for all the data to be stored in one place and accessed in the future for other research studies that address questions about mental health in young people. If other researchers would like to access this databank, they would have to apply to the Black Dog Institute Research Review and Advisory Group to be granted access, along with ethical approval. Any data provided would be de-identified so that your child's identity remains unknown. You can choose to not include your child's data in the databank by indicating your preference on the online consent form.



Publishing study findings

At the completion of the study, a summary of the research findings will be published in your child's school's newsletter and/or on the school's website. It will also appear on the [Black Dog Institute website](#), and the [Future Proofing Study website](#). In these publications, your child will not be identifiable from the information presented as data is shown in an aggregate format. Throughout the study, the research team will provide regular updates about the study's progress to your child's school, who will keep you updated.

If you have any questions/complaints or would like to withdraw

More detailed information about the study apps and requesting access to health and education records can be found on the [Future Proofing Study website](#).

If you have any questions or would like more information, feel free to contact **Dr Aliza Werner-Seidler** at any time by email at futureproofing@blackdog.org.au or phone **02 9382 3803**. If you wish to make a complaint, please contact the UNSW Human Research Ethics Committee by email: humanethics@unsw.edu.au or phone: 02 93856222 and quote the HC reference number HC180836.

If you would like to withdraw your child's participation in the study at any time, please fill in and return the withdrawal of consent form on the next page. You may also write an email to Dr Aliza Werner-Seidler at futureproofing@blackdog.org.au to withdraw. This will not affect yours or your child's relationship with the Black Dog Institute or UNSW now or in the future.

If you **would like** your child to participate in the Future Proofing Study...

To consent for your child to participate in this study please visit our secure online portal and complete the online consent form. Your child's school will share a website link for you to access the form that is unique to your school.

If you **do not want** your child to participate in the Future Proofing Study...

To ensure we do not contact you in the future about this study, please visit our secure online portal and indicate your preference along with your details via the online consent form. Your child's school will share a website link for you to access the form that is unique to your school.

Thank you for taking the time to read through this information sheet.

We hope you consider your child's participation in the Future Proofing Study.



Withdrawal of Consent Form

You may withdraw your consent for the Future Proofing Study at any time. You may also withdraw your consent for your child's data to be linked to existing government datasets and/or retained in the databank for future research purposes. You can do so by completing the appropriate 'Withdrawal of Consent Form' provided below. You do not have to give a reason. Alternatively, you can call or email the research team and tell them that you would like to withdraw your child using the details at the end of this page. Your decision to withdraw from the study will not affect your relationship with the University of New South Wales, the Black Dog Institute, or any other organisations involved in this study.

If you decide to leave the research study, the researchers will not collect additional information from your child. All participants who withdraw will not receive any further study updates or reminders from the study team.

Withdrawing consent for the Future Proofing Study

I wish to WITHDRAW consent for my child to participate in the research study described above.

Please indicate whether the researchers can retain your child's de-identified data up until this point:

- Yes, you can retain study information already collected about my child up until this point;
 No, I would like any information collected from my child for the purpose of this research project withdrawn.

Withdrawing consent for record linkage and/or data bank

- I wish to WITHDRAW my consent for my child's data to be linked to existing government datasets. I understand it is not possible to withdraw my child's information from the study results if my child's personal identifying details have already been removed*
 I wish to WITHDRAW my consent for my child's deidentified data to be stored in the databank for future research purposes*

*Please note, you can withdraw your consent for record linkage and/or the databank and allow your child to continue participate in the study without having their data used in these ways.

Name of Parent/Guardian	
Name of Child	
Signature of Parent/Guardian	
Date	

The section for Withdrawal of Participation should be forwarded to:

Name: Dr Aliza Werner-Seidler	Email: futureproofing@blackdog.org.au
Phone: (02) 9382 3803	Postal Address: Black Dog Institute, Hospital Road Randwick NSW 2031

