Dear Parents and Carers,

The Black Dog Institute invites you to enrol your Year 8 child in our largest ever research initiative, the Future Proofing Study. A world-first, this study aims to discover how we can put teenagers’ smartphones to positive use to drive mental health and wellbeing on a large scale.

What is the Black Dog Institute?

Founded in 2002, the Black Dog Institute is the only medical research institute in Australia dedicated to improving mental wellbeing across the lifespan. As leaders in app-based healthcare tools, we're a driving force in making help seeking and intervention accessible to all. Our research has a strong focus on youth and early intervention, where we use prevention programs to reach young people before mental health problems take hold.

Why do we need this study?

We know that 50% of all mental health problems emerge in adolescence, yet teenagers are unlikely to get help until these problems have an impact on school attendance, academic results and relationships. Even when these problems become obvious, many teens avoid seeking help due to cost, stigma and trouble finding the right services. By using app-based healthcare tools, we can put evidence-based mental health programs into the hands of all young people, whenever they need them and wherever they are.

What does the study involve?

Students in the study will complete online surveys about their mental health and wellbeing at school. There are two surveys in Year 8, and then one each year until Year 12. Students will also use apps to teach them skills to manage their wellbeing, and to teach us about the early signs of changing mental health. All students in the study will have their mental health screened and if they need support, we’ll link them in with the school counsellor.

How is privacy protected?

The Future Proofing Study has been approved by university and education ethics bodies. We adhere to strict ethical and privacy guidelines to run a study of this nature, where the participants’ wellbeing and data is of paramount importance. Your child’s information will be stored in a way that will not identify them.

How does my child sign up?

Students require consent from a parent or guardian to take part in the study. You can register your consent via a short online form. Your child’s school will send you a website link that is specific to your school.

Please refer to the attached Information Sheet for Parents for detailed information about the study. If you have any questions or concerns at all, please contact us at futureproofing@blackdog.org.au.

Yours sincerely,

Professor Helen Christensen
Director and Chief Scientist
Black Dog Institute
We know we can prevent depression in 22% of young people. However, a major problem is providing these prevention programs easily to everyone. At the Black Dog Institute, we are investigating mobile applications (apps) that could be used to help prevent depression in young people on a large scale. We are also interested in learning more about the health, wellbeing and experiences of young people to identify the factors that lead to depression and mental health problems. This landmark study is going to involve up to 20,000 young people across 400 schools in Australia. 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?

Information from the Future Proofing Study will lead to important new findings about the health and wellbeing of Australian young people, with the ultimate goal of helping future generations 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 know. All participating students will receive a $20 gift card.

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?

Aware of busy lives and the pressure and importance of schoolwork, our study has been designed to minimise impact on time required by students both in and out of school. Participating students will:

1. **Complete online surveys during school or in own time** three times in the first year and then once each year until Year 12. The surveys will ask about depression, anxiety, suicide, self-harm, drug and alcohol use, traumatic experiences, bullying, puberty, and from Year 10 onwards, sex. A final online survey will 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 the ‘Future Proofing’ app** which collects information about thinking skills, speech, mood and movement. Research shows that changes to cognition (thinking skills), speech, physical activity and sleep might be early indicators of deteriorating mental health. Collecting this information will help us work out ways to identify mental health problems at the earliest possible opportunity. 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 logic 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?

We don’t anticipate any risks to your child from taking part in this study. The online surveys ask about sensitive
topics including suicide and trauma. Research shows that asking about suicide does not increase suicidal thinking
or behaviour, rather, participation in suicide-related research reduces suicidal thinking. In the unlikely event your
child expresses thoughts or plans about suicide we will notify their school counsellor or nominated school staff
member immediately so they can check in with your child. If your child changes schools between now and Year
12, we will inform you about this information instead and provide you with details of support services in your area.

When your child is in Year 12, the survey content will also include questions about sexual abuse. Of course if your
child indicates any abuse 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?

Information will be collected via the online surveys and the Future Proofing app. The Future Proofing app collects information from your child about their mood, their performance on two logic games, a typing task, and audio recordings of their voice while they read out simple sounds (e.g., ‘Pa, Ka, Ta’). Their voice is only recorded when they activate and complete the inbuilt reading tasks. We have no ability to listen to or monitor calls or messages.

If and only if you and your child give specific permission on the consent form, the app will also use the phone’s sensors to take measurements of location (via GPS) and movement (via accelerometer and gyroscope sensors) over the first three months of the study. Collection of this sensor information is optional and does not affect your child’s ability to take part in the rest of the study.

We’re doing this because we think that these signals about behaviour – such as daily movement rhythms – could help us predict the risk of mental health problems and offer early intervention. If you do choose to opt in, we may ask your child for permission to collect further phone sensor information later in the study. This is also optional.

We will treat any data we collect in the strictest confidence. This means we will anonymise the data and, for GPS data, will process it so that no-one in the research team is able to identify the true locations measured by the phone.

For this study it would be ideal to access health and education records, which are already 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 to learn more about how changes to mental health affects physical health, health system usage and 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 app 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.
How will the study data be stored?

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. Any data provided would be de-identified so that your child’s identity remains unknown. You can choose not to include your child’s data in the databank.

When will the findings be published?

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.

What if I have more questions or a complaint?

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 the Trial Manager, Kate Maston, at any time by email at futureproofing@blackdog.org.au or phone 02 9382 9506.

If you wish to make a complaint, please contact the UNSW Human Research Ethics Committee by email: humanethics@unsw.edu.au or phone: 02 9385 6222 and quote the HC reference number: HC180836.
What if I want to withdraw my child’s participation?

If you would like to withdraw your child’s participation in the study after it has commenced, please fill in and return the withdrawal of consent form on the next page. You may also write an email to the lead investigator of the trial, 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.

Driving a mentally healthier world

Taking part in this study is an incredible opportunity to be part of a research project that has the potential to support young people and change the future landscape for young people’s mental health. 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.

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, we also encourage you to visit our online portal to register your decision to ensure we don’t contact you again about this 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.

**Withdrawal 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.

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<thead>
<tr>
<th>Name of Parent/Guardian</th>
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<tbody>
<tr>
<td>Name of Child</td>
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<tr>
<td>Signature of Parent/Guardian</td>
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<tr>
<td>Date</td>
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</tbody>
</table>

**The section for Withdrawal of Participation should be forwarded to:**

<table>
<thead>
<tr>
<th>Name: Dr Aliza Werner-Seidler</th>
<th>Email: <a href="mailto:futureproofing@blackdog.org.au">futureproofing@blackdog.org.au</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone: (02) 9382 3803</td>
<td>Postal Address: Black Dog Institute, Hospital Road Randwick NSW 2031</td>
</tr>
</tbody>
</table>