



The BrainWaves Adolescent Consent Study

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee Approval Reference: R86083/RE002

1. Introductory paragraph

BrainWaves is a new project about mental health and wellbeing led by the University of Oxford, in partnership with Swansea University (data informatics partners) and *The Day* (education partners). We would like to invite you to take part in an online survey to help us learn about young people's mental health and how best to get young people involved in health-related research.

Before you decide whether to take part in this study it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You are welcome to contact a member of the research team (please see details below) if there is anything that is not clear or if you would like more information.

2. Why is this research being conducted?

The main purpose of this study is to help us learn about the best way to **get young people's consent to participate in health-related research studies**. Right now, we know that many young people don't take part in research, sometimes due to concerns about their privacy or confidentiality. This means that not all voices are heard when we consider actions to improve young people's lives.

One thing that might influence young people's decision to take part in research is how we get their consent to participate and what information we give them about the research. Therefore, we want to explore five different ways of getting consent to take part in an online survey about mental health and wellbeing. We'll look at whether students' participation and answers in the survey differ by how we get consent. We'll also give students the opportunity to tell us about their views in focus groups following the survey.

We'll also use the information collected from the survey to explore key questions about young people's mental health and wellbeing. The data collected gives us the opportunity to learn about what contributes to good or poor mental health among young people, which can help us improve mental health in the future.

3. Why have I been invited to take part?

You have been invited to take part in this survey because your school is taking part in the BrainWaves project. All students in Year 12 and 13 who are at least 16 years old are being asked to participate. In total, we're hoping to get students from at least 12 secondary schools to take part in the online survey.

4. Do I have to take part?

It's up to you to decide whether to take part in the study. If you do decide to take part, you are still free to withdraw at any time during survey completion without giving a reason.

If you want your survey data to be deleted from our platform, you can contact the team at brainwaves@psych.ox.ac.uk with your request. This will lead to a new version of the dataset to be shared with researchers moving forward. (Please note that it is only possible to delete your data if you are randomly assigned to a version of the survey where you are asked for your name/identifying information – otherwise we will have no way of knowing which response is yours.)

5. What will happen to me if I take part in the research?

We'll ask you to complete an online survey about your mental health and wellbeing. Before you start the survey, the computer programme will randomly assign you to one of the five ways of getting consent. This means that the students in your school will have slightly different experiences of the survey, even though all of the questions will be the same. So, don't worry if you think your survey differed from your friends' surveys, as this is part of the study.

We expect that the survey will take you about 15-20 minutes to complete. It's important that you know what the survey will ask about. Topics include:

- Mental health and wellbeing
- Your views about yourself
- Abuse and neglect
- Loneliness
- School experiences
- Sharing of sexually explicit images/videos

We'll also ask you about whether you would hypothetically be happy for us to link the answers you provide in the survey to other information about you (e.g. education or health records). You can find some information about this in the consent form. You can still take part in the survey even if you say you would **not** want us to link your responses to other information about you. If we do end up linking data later on, you will get much more information about this so that you can make an informed decision before giving consent.

After you take part in the survey, your school will send you an invitation to take part in an optional focus group to share your views on consent, privacy, and confidentiality in research. You can take part in the online survey *without* choosing to participate in a focus group.

6. What are the possible disadvantages and risks in taking part?

The main possible disadvantage of taking part is that you might find some of the questions sensitive or distressing. We know from previous research that many things influence young people's mental health, including difficult life experiences such as abuse or neglect. Therefore, it is important that we ask about these experiences to see the full picture of mental health.

Although it would help us if you can answer all questions as accurately as possible, please remember that you *always have the option to skip questions or sections if you do not want to answer*. If you are upset or concerned about the survey questions, we encourage you to reach out to a trusted adult at home, at school, or elsewhere. We also provide some links to online resources at the end of the survey.

7. Are there any benefits in taking part?

There won't be any direct benefits to you in taking part in this survey. However, participation from you and your peers can help us learn about the best way to conduct research with young people in

the future. Currently, we don't know the best way to get young people to take part in studies like these, and understanding more about how to get consent can make sure that all young people's voices are heard in future research studies. This will mean that we can design better interventions and policies to improve the lives of young people across the country.

8. Expenses and payments

There will be no payment for taking part in this research.

9. What information will be collected and why is the collection of this information relevant for achieving the research objectives?

Data entry and processing for the online survey are fully automated through trusted research platforms at the University of Swansea. All data will be stored on secure servers at the University of Swansea. We will collect the following data:

- **Consent forms**
 - **Why?** We collect these in order to learn about who does and does not give consent to take part in research (see section 2). We keep them in order to record your consent to take part in the research.
 - **For how long?** These will be stored indefinitely so that we can always demonstrate participants' consent to take part in the research.
 - **Who will have access?** System administrators at the University of Swansea and the BrainWaves Study team will have access to these. Consent forms may also be accessed by University of Oxford and University of Swansea approved teams, such as the information compliance teams or auditing firms, only in case of audit or investigation. Consent forms will otherwise not be shared outside of the study.
- **Identifiable information – name**
 - **Why?** We collect these in order to link your responses over time as part of the wider BrainWaves Study (if you choose to participate in it) and potentially to link to other information about you in the future (if you choose).
 - **For how long?** These will be stored until the end of the wider BrainWaves Study (i.e. a minimum of 10 years), unless you ask us to remove them. We keep them this long so that you will have the opportunity to participate in the wider BrainWaves Study in the future if you choose to do so.
 - **Who will have access?** Only system administrators at the University of Swansea will have access to these (for the purposes of linking your responses).
- **Contact details**
 - **Why?** We collect these (with your explicit permission) to be able to get in touch with you to take part in future phases of the BrainWaves Study so that we can learn more about you and your experiences over time.
 - **For how long?** These will be stored until the end of the wider BrainWaves Study (i.e. a minimum of 10 years), unless you ask us to remove them. We keep them this long so that you will have the opportunity to participate in the wider BrainWaves Study in the future if you choose to do so.
 - **Who will have access?** The BrainWaves Study team will have access to these details but *will not share them outside of the study without your permission.*

- **Survey data (including 'special category data' on your basic demographics (e.g., gender, birth month and year), and health and wellbeing, see section 5)**
 - **Why?** Collecting these data is the main reason we are doing this study and we will analyse them in different ways. First and foremost, we want to learn whether responses differ based on the version of the survey assigned. We also want to use the data to explore key issues and trends in youth mental health and wellbeing.
 - **For how long?** Data will be kept in **de-identified form** (i.e., without your name) indefinitely so that we can continue to learn from them for years to come.
 - **Who will have access?** The BrainWaves Study team will have access to your de-identified survey data. Other researcher teams may access the de-identified data upon approval by a committee (including members of the BrainWaves Study team, young people, and others).

10. Will the research be published? Could I be identified from any publications or other research outputs?

The findings from the research may be written up in academic publications, conference presentations, and summaries for students, schools, and the general public. Your identity will **not** be revealed in any articles, presentations, or other published materials.

11. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the research. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available from the University's Information Compliance web site at <https://compliance.admin.ox.ac.uk/individual-rights>.

12. Who is funding the research?

This study is funded through philanthropic support to the BrainWaves project and the John Fell Fund at the University of Oxford.

13. Who has reviewed this research?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: R86083/RE002).

14. Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this research, please contact the BrainWaves team at the University of Oxford (brainwaves@psych.ox.ac.uk) or Professor Mina Fazel (mina.fazel@psych.ox.ac.uk), and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

The Chair, Medical Sciences Interdivisional Research Ethics Committee;
Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

15. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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