The BrainWaves Study Team
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# The BrainWaves Cohort Study

# Participant information sheet

Central University Research Ethics Committee Approval Reference: R91383/RE007

**Introductory paragraph:**

BrainWaves Research is a registered charity (number: 1213437) in England and Wales created to research ways to improve mental health and wellbeing. The BrainWaves Cohort Study is a study run by the University of Oxford, in partnership with Swansea University and *The Day News and Media* (a digital publisher for schools).

We are inviting you to take part in an online mental health and wellbeing questionnaire (the 'Cohort Study') through your school / college to help us learn more about young people's mental health and wellbeing. . In addition, we will send you occasional study updates as the study progresses. We may also invite you to take part in other BrainWaves studies, but for these we won't contact you more than twice a year.

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 a trusted adult or friend 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. Note that all questionnaire data will be pseudonymised. This means that data will be labelled with a code instead of your personal details and a linkage key will be stored separately on secure servers, and your school will not be able to match you with your questionnaire responses.

<u>This questionnaire is confidential.</u> This means that 1. Your answers will not be linked to your name; 2. your answers (not your name or contact information) will only be seen by the research team. The answers will not be shared with your school, parents, or carers.

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**Why is this research being conducted?**

- To help us understand how best to promote mental health and wellbeing in young people.
- To provide researchers with in-depth knowledge on young people's mental health.
- To help develop lessons and resources for schools to support the good mental health of their students.

**Why have I been invited to take part?**

You have been invited to take part in this questionnaire because your school / college is participating in the BrainWaves project. You are in one of the year groups we are offering the study to this year, and are at least 16 years old.

**Do I have to take part?**

No, you do not have to take part if you don't want to. If you do decide to take part and then change your mind, you can stop taking part at any time without giving a reason.

**What will happen if I take part in the research?**

We'll ask you to create a login using your personal email address (so that we are able to re-contact you) and complete an online questionnaire about your mental health and wellbeing. We will also ask you to provide your mobile phone number as a backup contact method. You will be given time in school / college to answer this questionnaire, but it does not matter if you don't quite finish. The questionnaire will ask you about the following topics:

- Mental health
- Wellbeing
- Lifestyle including substance use, self-harm and eating behaviour
- Health
- Adversity you may have experienced (such as maltreatment and abuse)
- Social relationships, including sexual and romantic relationships

**What are the possible disadvantages and risks in taking part?**

Some of the questions may feel sensitive or personal , but we ask about these topics because we have heard from young people who work with BrainWaves that they are topics important to them.

We also want to make sure we research in as much detail as possible, so that we can help in the best way possible.

You always have the option to not answer questions or sections if you do not want to. If you are upset or concerned about any of the questionnaire questions, we encourage you to reach out to a trusted adult at home, at school / college, or elsewhere. We provide some links to online resources at the end of the questionnaire.

You will also have the option to tick a box during the questionnaire to indicate that you would like to be contacted by the BrainWaves team with a range of support options. When contacted, you will be given some options to choose from to receive further support, including a referral letter to take to your GP, further online signposting and support materials, or referral to your school/college Designated Safeguarding Lead. We will contact you via email within 5 working days (Monday - Friday) of you requesting support and we will make 3 attempts to reach you.

**Are there any benefits in taking part?**

Being part of BrainWaves is something that helps others. You will be giving your time and data to help researchers make discoveries about young people's mental health and wellbeing, and to develop better ways of supporting young people in their journey to adulthood. You will also receive a certificate from BrainWaves with the Oxford University logo on it. Lastly, you will be making a difference to young people everywhere and for many years to come by sharing your experiences.

**Expenses and payments**

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

**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, which isResearch is a task that is performed for the benefit of society and communities. 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.

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**What information will be collected, why and who will be able to see it?**

Data processing and storage are fully automated through trusted online research platforms at Swansea University. We will collect the following data:

| What the information is | Why we are collecting it | How long it will be stored for | Who will be able to see it |
|---|---|---|---|
| **Your consent form** | To learn about who does and does not give consent to take part in research. | Continually so that we can always demonstrate participants' consent to take part in the research. | Only a small number of approved staff who work with the data. |
| **Personal details about you (for example, your date of birth)** | To be able to link your data to other information about you, for example, your school/college records. | For at least 10 years (the duration of the cohort study). You can ask to remove your data from the study by contacting us. | Only a small number of approved staff who work with the data. |
| **Contact details (your email address)** | So you can log in to the BrainWaves study platform To take part in future data collection windows. | For at least 10 years (the duration of the cohort study). You can ask to remove your data from the study by contacting us. | Only a small number of approved staff who work with the data. |
| **Questionnaire data (including data on gender, age, health and wellbeing).** | To better understand young people's mental health and wellbeing. | Data will be kept without information that can identify you, for example your name and email. Data will be kept continuously so that we can keep learning from your experiences. | Only approved researchers. If you want your questionnaire data to be removed, you can contact us at brainwaves@psych.ox.ac.uk. Please note that we cannot remove data that are already used in analyses. |

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**Will the research be published?** Data collected from the Cohort Study questionnaire in previous years has been used in research and published in different formats. Data from this Cohort Study will be used exclusively for research purposes and academic publications, conference presentations, and summaries for students, schools, and the general public. All findings are screened to ensure that individuals are not identifiable.

**Who is funding the research?**

This study is funded through philanthropic (donated) support to the BrainWaves project.

**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: R91383/RE006).

**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 John Gallacher (john.gallacher@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 University of Oxford Research Governance, Ethics & Assurance (RGEA) team at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

**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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