The BrainWaves Study Team
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The BrainWaves Cohort Study

School Leavers Participant information sheet

Central University Research Ethics Committee Approval Reference: R91383/RE007

Introduction

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 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') which you previously completed through your school / college to help us learn more about young people's mental health and wellbeing. **In addition, we will send you a study update every few months.** 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 again, 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. 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.

The questionnaire is confidential. 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. Your answers will not be seen by anyone else: not your family, carers or the school or college you originally participated with.

Why is this research being conducted?

- To help us understand how best to promote mental health and wellbeing in young people.

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- To provide researchers with in-depth knowledge on young people's mental health.
- To inform the development of interventions to promote good mental health.
- To inform the development of teaching materials that support good mental health.

Why have I been invited to take part?

You have been invited to take part in this questionnaire because you previously participated in the BrainWaves project while still in school / college. We are now inviting you to continue your participation and take part in this follow-up questionnaire.

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 log back into the account you created previously (there is an option for forgotten passwords). You will then be asked to complete the annual online questionnaire about your mental health and wellbeing. We will also ask you to provide your mobile phone number as a backup contact method. We suggest that you allocate approximately 20 minutes in total to answer this questionnaire. The questionnaire will ask you about the following topics:

- Mental health
- Wellbeing
- Lifestyle, including substance use, self-harm and eating behaviour
- Cognition (thinking processes)
- 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 be sensitive or personal , but we ask about these topics because we know from previous research that difficult life experiences such as maltreatment or discrimination affect mental health in young people.

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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 questions, we encourage you to reach out to a trusted adult or friend at home or elsewhere. We provide some links to online resources at the end of the questionnaire. You will also be provided with the option to request to be contacted by someone about some of the questions. When contacted, you will be given some options to choose from to receive further support, including a referral letter to take to your GP, or further online self-help materials. We will contact you within 5 working days 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. This will allow yours and future generations to live happier and more fulfilling lives.

You will also be given the opportunity to enter a prize draw upon completion of the questionnaire. You will have the opportunity to win one of 10 prizes. Clear instructions will be given on the online data portal as to how to enter the competition as well as the terms and conditions. Your entry into the competition will be kept separate from your answers to the questionnaire and we will not be able to link your questionnaire responses to your competition entry. The winners will be chosen at random one week after the completion of the data collection window.

Expenses and payments

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

What information will be collected and why is this information relevant to the study?

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

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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.

Will the research be published?

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Findings from the research have already been 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.

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.

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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