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The BrainWaves Cohort Study

Participant information sheet

Central University Research Ethics Committee Approval Reference: R91383/RE005

1. Introductory paragraph

BrainWaves is a new registered charity (number: 1213437) in England and Wales created to lead a project about mental health and wellbeing. BrainWaves is run by the University of Oxford, in partnership with Swansea University and *The Day* (a digital publisher for schools). BrainWaves aims to investigate young people's mental health in order to improve the quality of scientific knowledge surrounding this research area and assist young people with the management of their mental health challenges. We are inviting you to take part in a cohort study, which will consist of annual online questionnaires 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 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, and your school will not be able to match you with your questionnaire responses.

2. 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 inform the development of interventions to promote good mental health.
- To inform the development of teaching materials that support good mental health.

3. Why have I been invited to take part?

- You have been invited to take part in this questionnaire because your school is participating in the BrainWaves project.
- Your school has been invited to support BrainWaves as we need a wide selection of schools if the study is to be helpful to a wide range of young people.
- All students in Year 12 and 13 who are at least 16 years old are being asked to participate.

4. 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.

5. What will happen to me 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 annually. We will also ask you to provide your mobile phone number as a backup contact method. You will be allocated

approximately 40 minutes in total 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
- Cognition (thinking processes)
- Health
- Adversity you may have experienced (such as maltreatment and abuse)
- Social relationships, including sexual and romantic relationships

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

Some of the questions may be sensitive or distressing, 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.

- 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, 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, an initial phone call with a chartered psychologist (a member of the BrainWaves team), further online self-help materials, or referral to your school safeguarding lead. We will contact you within 5 working days of you requesting support and we will make 3 attempts to reach you.

7. 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.

8. Expenses and payments

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

9. 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:

- **Consent forms**
 - **Why?** To learn about who does and does not give consent to take part in research.
 - **For how long?** Indefinitely, so that we can always demonstrate participants' consent to take part in the research.
 - **Who will have access?** System administrators, information compliance teams, auditing firms and the BrainWaves study team members. Consent forms will not be shared outside of the study.
- **Identifiable information (such as your contact details and education records)**
 - **Why?** To link your responses over time as part of the wider BrainWaves Study. We also ask for your school linking number to be able to link to attendance data from your school, in order to gather valuable information about how these aspects may be related.

- **For how long?** For the duration of the study (at least 10 years), unless you ask us to remove them.
- **Who will have access?** Only system administrators at Swansea University will have access to these (for the purposes of linking your responses). Researchers will not have access to these.
- **Contact details**
 - **Why?** To be able to recontact you for future phases of the BrainWaves Study.
 - **For how long?** For the duration of the study (at least 10 years), unless you ask us to remove them.
 - **Who will have access?** The BrainWaves Study team will have access to these details but we *will not share them beyond the study without your permission, including with your school*.
- **Questionnaire data (including data on your basic demographics (e.g., gender, age), and health and wellbeing, see section 5)**
 - **Why?** To explore key issues and trends in youth mental health and wellbeing.
 - **For how long?** Data will be kept in pseudonymised form (i.e., without your name or email) indefinitely so that we can continue to learn from them.
 - **Who will have access?** The BrainWaves Study team and approved researchers will have access to your pseudonymised questionnaire data. As The Day is only responsible for recruiting participants, they will not act as data processors and therefore, will not have any access to the data.
 - If you want your questionnaire data to be deleted from our platform, you can contact the team at brainwaves@psych.ox.ac.uk with your request. Please note that data cannot be removed from analyses that are completed or underway.

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

Findings from the research will be used exclusively for research purposes and may be published in academic publications, conference presentations, and summaries for students, schools, and the general public. All findings are screened to ensure that individuals are not identifiable.

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 (donated) support to the BrainWaves project.

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: R91383/RE005).

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 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.

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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