

INFORMATION SHEET FOR PARENT/GUARDIAN

PARTICIPATING IN RESEARCH

Study title:

Digital support for young people with their mood and well-being



Invitation

We would like to invite young people and their parents/carers to take part in a study on ways of supporting young people with their mood and wellbeing. Before you decide whether you are happy to take part it is important that you 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. We are happy to answer any questions – our contact details are at the end.

Thank you for reading this.

What is the purpose of the study?

Many young people have problems with mood, and most are not getting any help. We are now looking at different ways in which to help young people online with their health, mood and well-being.

We have developed an online programme/app with young people and families/carers to support their mood and well-being (please find details of the programme [here](#)). We are interested in how young people and parents/carers might use this, compared to using a digital information pack for mood and well-being, together with any help the young person is getting (e.g. school counselling).

It is important to get feedback from young people and parents/carers so that we know how to improve and test this programme further. If found to be effective, the programme could be made freely available in future.

Who are the researchers?

We are doctors and researchers at Cardiff University and the University of Glasgow, with a lot of experience of working in the field of young people's mental health and digital technologies.

Who can take part in this study?

1. We are looking for young people between 13 and 19 years of age who have had problems with their mood and wellbeing (e.g. feeling down or low in mood) and have regular access to the internet.

It does not matter whether the young person has other forms of help (e.g. school counselling). However, we are looking for young people who are not under the care of secondary child and adolescent mental health services (CAMHS) and do not have other severe mental health difficulties (apart from depression or anxiety).

2. We would also like to ask their parents/carers whether they would like to take part.



Do I have to take part?

No, it is up to you to decide whether or not to take part. If you take part, you will be asked to provide consent.

You are free to withdraw at any time and without giving a reason. Withdrawing from the study will not affect your (or your child's) health care or legal rights in the future. You can contact the researchers to let them know you would like to stop taking part.

What will happen if I take part?

This shows what will happen if you are happy to take part:

Start of project:

1. Fill online form, talk to us about the project & give consent to take part.
2. Fill online questionnaire about your mood and wellbeing (25-30 minutes).
3. Receive link to online programme/app OR digital information pack.



Two months after starting:

4. Fill the same online questionnaire.
5. If you used the programme, answer extra questions on your feedback (10-15 minutes).

Two-thirds of young people and parents/carers in the study will have access to the online programme and a third will receive the information pack. To make the decision fair and to keep this proportion, a computer will decide in which group you will be placed.

You can use the programme or pack as much as you like – on your own or with someone else (e.g. your child or partner). You don't need to fill the online questionnaires all at once or in one go – you can 'save' your answers and finish them later.

If you used the programme, we will monitor online *how* you are using it (e.g. how often you log in), but not *what* you enter into it (e.g. how you are feeling), for 6 months from the start of the project.

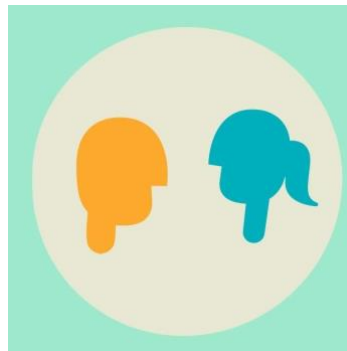
Does anything else happen if I take part?

After around two months, if you used the programme, we might ask you whether you would like to meet one of the researchers for around 30-60 minutes to discuss your feedback on this. This will be by video conferencing (e.g. Zoom, Skype or MS Teams), by phone or face-to-face.

We will audio record the meeting on an encrypted voice recorder. We might send the recordings without any of your personal details, to a professional company to be typed.

We will analyse the feedback to improve the programme. Some of things we might ask include:

- How easy was the programme to use?
- What did you think of the information in the programme?
- What did you think of the graphics, illustrations and animations?
- Did you find it helpful?



If you live in Wales, we would also like to ask permission to link the information you provide us from the questionnaires to information collected routinely by the NHS and other public organisations (e.g. GP, hospital and education records) in an anonymous way. An example of such a databank that we will link to in Wales is the Secure Anonymised Information Linkage (SAIL) dataset at Swansea University. All data linkage is done in line with the Data Protection Act and University governance.

If you agree, this will help us to understand further how the information pack and online programme might help young people and their families/carers.

As a 'thank you' for taking part and for their time, we will give you a £10 gift voucher for joining and filling the first questionnaire and a £10 voucher for filling the questionnaire after two months. We will give you another £10 voucher for taking part in a meeting about the programme. Your child will also receive vouchers if they take part.

What are the possible benefits of taking part?

We hope you will find it helpful and interesting to take part in the study. You might help to improve the care of young people by testing a programme to help with their mood and well-being.



Are there any possible disadvantages?

During the early testing of the programme, young people and parents/carers did not describe any difficulties.

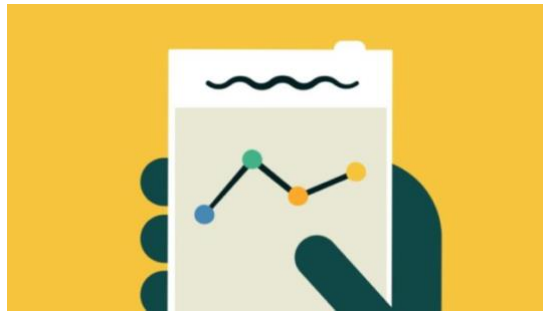
It is possible that some might find it difficult to think about mental health problems, when taking part in the project. We will try to avoid this as much as possible. We will arrange for meetings to be as convenient and comfortable as possible. The meetings will be focused on the programme, and not on your personal experiences or history of mental health difficulties.

If after taking part you feel the need for support, you can get in touch with us at any time. We will then discuss the problems with you and whether you need to talk to someone else, such as your GP.

What about confidentiality?

All information that is collected about you and your feedback will be kept strictly confidential and will be used for research purposes only. You will be identified by an ID number, and any information about you will have your name and contact details removed so that you cannot be identified from it.

If you use the online programme, you will have a unique username and create your own password to log into it. The site will be secure, and you will not be expected to enter personal information. There is a 'mood diary', where you may enter sensitive information, such as how you or your child are feeling. However, this will be confidential and we will not collect that information.



We will ask for the contact details of your family doctor or your child's family doctor. The only time we would contact a GP or other practitioner would be the rare circumstance of an extremely serious, urgent clinical concern (e.g. high suicide risk or child protection issues), or if there is a risk to you or others.

All the details and information from the study will be stored in approved and secure archiving facilities (in locked cabinets or secure computers), in line with the [University's Information Security Framework](#).

What if something goes wrong?

If you or your child have a concern or feel that you have been harmed in any way by the study, you should ask to speak to the researchers at Cardiff University at YouthOnlineStudy@cardiff.ac.uk, who will do their best to help. If you live in Scotland, you can also contact the study team at the University of Glasgow at sphsu-phrf@glasgow.ac.uk.

If you remain unhappy, and wish to complain formally, you can contact Dr Catrin Lewis, an independent researcher at the National Centre for Mental Health (lewisce7@cardiff.ac.uk).

What will happen to the results of the research study?

The results will help to develop the programme and help us plan more studies. The results will be summarised in university newsletters, health journal articles and a report for the organisations funding this research – this would be to help inform healthcare, education and other practitioners involved in the care of young people and their families/carers.

Some ideas and direct quotes from the questionnaires or meetings might be used in these reports. The information will be made anonymous, and your personal details will not appear on any of these documents and you will not be identifiable in any way.

Who holds my information?

Your information will be held by Cardiff University. The university is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. If you are in Scotland, some of your information will also be held by the University of Glasgow.

How will my information be used?

We will need to use information from you for this research project. This information will include your initials, name, contact details, date of birth, and GP details. If you will be accessing the online programme, we will collect app and website usage statistics which is hosted and managed by a third-party company (Google, Inc.). Usage information is collected to help improve the programme in the future. We will collect your device's IP address (your PC's/device's unique address when connected to a network) to ensure network and information security. However, we will not link your device's IP address to other data which we are collecting. Nor will we analyse the data unless we have specific reason to look at an individual IP address.

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Some of your information might be sent from Cardiff University to the University of Glasgow for analysis by health economists. The information will be anonymised, so it will not be possible to identify you from this information. They must follow our rules about keeping your information safe.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have and use this for the remainder of the study – unless you ask for it be removed. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. We are required to store your data for 15 years.

The data generated as part of this trial may be shared with other researchers in the future and this data will not identify you by name (pseudonymised data). Any future research using this data will be in the interest of public health and care.

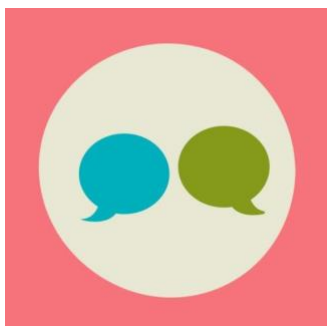
Where can I find out more about how my information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team

If you would like to complain about how researchers have handled your information, you should contact the research team. If you are not happy after that, you can contact the Data Protection Officer at Cardiff University at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's

Office should you wish to complain, can be found at the following: [Research participants data protection notice – Public information – Cardiff University.](#)



Who is organising and funding the research?

This study is led by Dr Rhys Bevan Jones and Professor Frances Rice and the Centre for Trials Research, at Cardiff University, and Professor Sharon Simpson at the University of Glasgow. The research is funded by the National Institute for Health Research, and Health and Care Research Wales.

Who has reviewed and approved the study?

NHS Research Ethics Committee, the National Institute for Health Research, Health and Care Research Wales and Cardiff University.

If you have any questions:

For the main study team, please contact YouthOnlineStudy@cardiff.ac.uk

Division of Psychological Medicine and Clinical Neurosciences, Cardiff University School of Medicine, Hadyn Ellis Building, Maindy Road, Cardiff CF24 4HQ

If you live in Scotland, you can also contact the study team at the University of Glasgow at phsu-phrf@glasgow.ac.uk.

Thank you for your interest in this study