

## INFORMATION SHEET FOR YOUNG PERSON

### Study title:

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



### Part 1 – to introduce you to the project

#### Invitation

We would like to invite you to take part in a study on ways of supporting young people with their mood and wellbeing. Before you decide if you want to take part, 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. Discuss it with others if you wish. We are happy to answer any questions – our details are at the end.

Thank you for reading this.

#### Why are we doing this research?

- Many young people have problems with mood, and most are not getting any help.
- 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 might use this, compared to using a digital information pack for mood and well-being, along with any other help they are getting (e.g. school counselling).
- It is important to get feedback from young people 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.
- We have worked on lots of projects with young people to support their mental health.

### Who can take part in this study?

1. Young people who:
    - are between 13 and 19 years of age
    - have had problems with their mood and wellbeing (e.g. feeling down or low in mood)
    - have regular access to the internet.
  - It does not matter whether they have 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 severe mental health difficulties (apart from depression or anxiety).
2. Their parents and carers



### Do I have to take part?

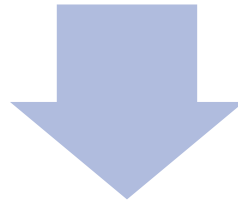
- No, it is up to you to decide whether or not to take part.
- If you are happy to take part, you will be asked to provide consent. Your parent/guardian will be asked to provide consent if you are under 16 years old.
- You are free to stop taking part at any time during the project, and without giving a reason. If you decide to stop taking part, this will not affect your health care or legal rights in the future. You can contact the researchers to let them know I 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).

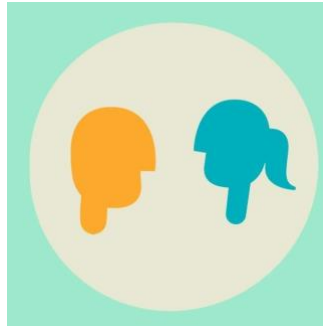
Two-thirds of young people will access the online programme, and a third will receive the information pack. To make the decision fair and to keep this proportion, a computer will decide which group you will go into.

You can use the programme or pack as much as you like – on your own or with someone else (e.g. counsellor, parent/carer or friend). 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 whether you would like to meet one of us for around 30-60 minutes to discuss your feedback on it.
- This will be by video conferencing (e.g. Zoom, Skype or MS Teams), by phone or face-to-face. A parent or guardian should be with you if you are under 16 years old.
- 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 your feedback to improve the programme. Some of things we might ask you 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 your permission to link the information you give us in 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 a databank that we will link to in Wales is the 'Secure Anonymised Information Linkage' (SAIL) dataset at Swansea University. This follows the Data Protection Act and University governance.
- If you agree, this will help us to understand further how the information pack and programme might help young people and families/carers.
- As a 'thank you' for taking part and for your 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. If your parent or carer takes part, they will also receive vouchers.

**Thank you for reading so far – if you are still interested, please go to part 2. If you would like more information, our contact details are at the end.**

## PART 2 – more information if you'd like to 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 discuss the problems with you and whether you need to talk to someone else, such as your family doctor.

### Will anyone else know I'm doing this?

- The information that is collected about you and your feedback will be strictly confidential (private) and will be used for research purposes only. This means it is between you and us (your parent/guardian will also know you are taking part if you are under 16 years old).
- 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 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. The only time we would contact them would be the rare situation where we were concerned about your safety or the safety of others (e.g. if you or they expressed thoughts of harming themselves 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 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](mailto: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](mailto:sphsu-phrf@glasgow.ac.uk).

- If you are still unhappy, please speak to your parent/guardian.
- If you then wish to complain formally, you can contact Dr Catrin Lewis, an independent researcher at the National Centre for Mental Health ([lewisce7@cardiff.ac.uk](mailto:lewisce7@cardiff.ac.uk)).
- If you are under the care of mental health services, you can contact the NHS complaint system.

### What will happen to the results of the study?

- These will help to develop the programme and help us plan more studies.
- Some ideas and direct quotes from the questionnaires or meetings might be used in study reports.
- The information will be made anonymous - it will not be possible to work out who took part.

### 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 live 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 or information 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/](http://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](mailto: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?

- Organisers: Dr Rhys Bevan Jones, Professor Frances Rice and the Centre for Trials Research at Cardiff University, and Professor Sharon Simpson at the University of Glasgow.
- Funders: National Institute for Health Research, and Health and Care Research Wales.

### Who has reviewed and approved (checked) the study?

NHS Research Ethics Committee, 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](mailto: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 [sphsu-phrf@glasgow.ac.uk](mailto:sphsu-phrf@glasgow.ac.uk).

**Thank you for your interest in this study**