



## Participant Information (13-18 years of age)

### **Youth Health Connections: JournHey? app deployment and testing**

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The JournHey? app is part of a research project led by Dr Andrew James Williams at the University of Edinburgh. The app is for 8-18 year olds and the information you provide within the app will be used for health research. Helping us to understand and improve the influences on your health. Please read this document carefully. It is really important to us that you understand and agree with how we will use your data. Please contact the research team (email at the end of the document) if you have any questions.

#### What is the study about?

For researchers and decision makers to be able to identify when something is harmful or helpful for your health, we need data. The data needs to include information collected around the same time on health and whatever influence might be harmful or helpful. We (the research team listed at the top of the page) have worked with young people in schools and youth groups to design the JournHey? app to collect this kind of data. We know that it is important for you to find the data useful so the following features are part of the app:

- You will be able to create graphs of your data over time and compared to the influences you log. This approach is called citizen science, as you will be the scientist analysing your own data.
- You will be able to chat with other app users about the influences on your health. When you find other young people experiencing the same influence you will then get the chance to create a petition asking for changes to be made. This approach is called crowdsourcing as you will be asking lots of other young people for their thoughts and ideas, and working together to ask for changes.

Researchers will use the data you provide to build up evidence for how to make communities and neighbourhoods healthier places. When we do this the data will be anonymised meaning that anything which would identify you will have been removed. As a new app we are also keen to hear what you think about it. So, we will be sending users a feedback survey to help us modify and improve the app.

#### Why have we been invited to take part?

You have been invited to participate as a young person interested in using the JournHey? app. You may have heard about the app through your school, youth group, friends or family.

#### Do I have to take part?

No, it is up to you to decide whether you wish to take part. If you are aged 15 years or less, we also need your parent or guardian's permission for you to use the app, so please discuss the project with them. If you are aged 16-18 years and live in England (but not Scotland), we also need your parent or guardian's permission. This information sheet has been written to help you decide whether to take part. If you do

decide to take part you will be free to withdraw at any time without providing a reason. Deciding not to take part or withdrawing from the study will not affect your medical care or legal rights.

### What does taking part involve?

If you do decide to take part, please keep this Information Sheet. Taking part in the study involves installing the JournHey? app on your mobile phone. When you register with the app you will firstly be asked to complete a consent or assent form. Giving your consent or assent shows that you understand your rights in relation to the research, and that you are happy to participate.

You will be asked to provide your name, date of birth, gender, postcode and an email address we can use to contact you. If we need your parent or guardians' permission for you to use the app, we will also ask for their name and email address. This is so that we can send them a document like this one and an online consent form for them to complete.

You will also be able to select an avatar to use in the app and list some of your interests (e.g., sports, music, foods). Once registered in the app there are the following functions:

1. Daily check-in: This is four sliders on the main app screen on your diet, exercise, sleep and wellbeing. Whenever using the app, you can move each slider up and down depending on whether you feel that recently each of those areas of your life have been more or less healthy.
2. Daily question: Each day you will get a notification about a new question for you to answer. Like the daily check-in sliders these questions are about your diet, exercise, sleep and wellbeing. They are questions used in other research projects and will help us compare your data with other statistics. Most days it will just be a single question that you can answer quickly. Once a week the question will ask about the influences on your health that week. Once a month it will be a longer set of questions.
3. Level, points and streak: For each of the activities you do in the app you will collect points. We will also let you know you streak of using the app every day. You will also move up levels of expertise as you use the app.
4. Viewing your health data: In this part of the app, you will be able to use graphs to look back over the history of your daily check-in responses. You can use this to see how things are changing over time and how your diet, exercise, sleep and wellbeing might be related to each other. You will also be able to compare your data with the influences you have experienced, to see what impact they have had.
5. Topics: This is the discussion board part of the app. Here you can start discussions about the influences you have found that made your diet, exercise, sleep and wellbeing better or worse. You will need to decide whether the discussion relates to: time, physical spaces, headspaces, other people, costs or other. When you post a discussion you and anyone responding will not be identifiable, but you can choose whether to list your gender, age group, approximate location or an interest to help other users understand the post. You will be able to follow and respond to the posts made by others. As you will be writing and responding to other young people you will need to think about how they might react. Make sure you don't share anything you don't want others to know. Each post will be reviewed by a member of the research team before it is posted to make sure it is safe to share.
6. Petitions: If lots of people join a discussion about similar experiences, you can ask to start a petition. A petition is when lots of people sign up to indicate that they want something to change. The petition will relate to an influence on your health and you will be asked to say who needs to make the change you want (e.g., your head teacher, a politician, etc.). You won't see the names of

the people who sign the petition inside the app, but the person receiving the petition will be told the number, age groups and approximate locations of the signatories.

7. Profile: This is where you can update your profile information and change your avatar. If you give permission for the app to collect data on your exercise levels automatically from the phone, or to access the photos on your phone then this can be turned off from your profile screen. If you have any problems with the app these can be reported using an email address on your profile screen.

We hope you will complete the check in and questions daily as well as reviewing or commenting on topics when you have time. But have tried to design the app so it won't take up much of your time. All the other users of the app are young people like you. We would like you to try to use the app for three months, but you are welcome to use the app for longer if you want. Once a month, for the first three month we will email you a short feedback survey so you can give us your opinion on the app and any suggestions you have, this will take 5-10 minutes to complete. We will link your survey responses to the information you have given us on your age, gender and location to help us understand if the app is working better for some young people than others.

#### What are the potential benefits of taking part?

The app is designed to help you learn about your health habits. It also gives you the opportunity to work with other young people to identify and take action on those things that influence your health. We also hope you will learn about the research process and enjoy using the app. As a thank you for the time and effort required to participate in the research, we will offer you a £15 shopping voucher after your first month (4 weeks) of use if you use the app at least once a week.

#### Are there any risks associated with taking part?

Within the app you will be collecting data on your diet, activity, sleep and wellbeing, which is sensitive data. So, it is not possible within the app to share these data with others, and we discourage you from doing this outside the app. When the researchers analyse the data, we will make sure that none of the people providing data can be identified. You will also be chatting with other users about the influences on your health, and there are risks related to this. For example, as you will be writing your own comments you want to make sure people cannot tell who you are from your comments. We will check comments to make sure all the users are kept safe, a process called moderation. But if we spot anything that concerns us, we will email you with links to appropriate support organisations.

The project lead, Dr Andrew James Williams and Dorothy Currie and Lynsey Brown have been cleared through the Disclosure Scotland Protecting Vulnerable Groups (PVG) scheme to work with children.

#### Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. The research team will not disclose information about who participated in the study to anyone.

#### How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Gender

- Date of birth
- Postcode
- Email address
- School (if used as part of a school project)

We will need to use the information you provide within the app to help administer the app and for research. 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. It is useful for us to have your postcode as this allows the researchers to look at data about your neighbourhood. This neighbourhood data includes whether it is in a rural or urban area and how many people live there. But we will contact you to suggest ways that your approximate location could be identified in the app, and you can select the one you prefer. You can then use this if you are starting a topic about an influence only relevant to people who live near you. We will keep all information about you safe and secure.

Your data will only be viewed by the research team. All the data gathered using the app and evaluation form will be anonymised before being used for research. This means that parts of the data will be edited or deleted such that no-one, including the researchers, could use any reasonably available means to identify you from the data. All electronic data will be stored on a safe and secure university server only accessible to the research team. Your consent information will be kept separately from your responses in order to minimise risk. If you collect data in the app for a school project, the data you provide within the project will be used to create an anonymised report for your teacher or school. No individual level data will be shared with the school and the research team will make sure that no one can be identified from the summary report.

#### What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason. To do this you need to close your account in the app and uninstall it. This will delete any not yet anonymised data you have submitted through the app, but your anonymous discussion posts and signing of petitions will not be deleted.
- Once a month the research team will take a backup copy of everyone's data from the app. These backup copies will be anonymised so that no one can be identified. This also means that it will not be possible to delete your anonymised data, if you leave the study.
- We will contact you annually to check that you continue to consent to being part of the project. If you stop consenting to be part of the project your account will be closed and your identifiable data will be deleted, apart from petition signatures.
- 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.

#### Where can you find out more about how your information is used?

You can find out more about how we use your information

- At <https://data-protection.ed.ac.uk/privacy-notice-research>
- by asking one of the research team
- by sending an email to the University of Edinburgh Data Protection Officer at [dpo@ed.ac.uk](mailto:dpo@ed.ac.uk)

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of

Edinburgh will keep identifiable information about you for as long as you remain a user of the app and provide consent. But this data would be deleted as soon as you close your account and stop using the app. We will keep your anonymised data for a minimum of 10 years.

#### How will my data be used, and how will the results of the study be used?

The data will be analysed as part of the research study. It will then be published in research publication(s)/conference proceedings. Other researchers will be able to apply to use the data. These researchers will need to demonstrate that they are asking a relevant research question and have ethical approval for their study. They will only be given access to anonymised data. When published the data will be in an anonymised form, which means that no-one could use any reasonably available means to identify you from the data. With your consent, your anonymised information may also be kept for future research. A summary of the research findings will also be posted on the app discussion board and project website (<https://health.ed.ac.uk/research/current-research/crowdsourcing-for-adolescent-health>).

#### Who is organising and funding the research?

This study has been organised by the research team listed at the top of the first page of this document, led by Dr Andrew James Williams and sponsored by the University of Edinburgh. Our research is being funded by the Medical Research Council, UK Research and Innovation.

#### Who has reviewed the study?

The study proposal has been reviewed by the University of Edinburgh School of Health in Social Science Research Ethics Committee (approval code: 24-25NUST001).

#### Who can I contact?

If you have any further questions about the study, please contact the lead researcher, Dr Andrew James Williams ([andrew.j.williams@ed.ac.uk](mailto:andrew.j.williams@ed.ac.uk)).

If you would like to discuss this study with someone independent of the study, please contact Dr Stephen Malden ([stephen.malden@ed.ac.uk](mailto:stephen.malden@ed.ac.uk)).

If you wish to make a complaint about the study, please contact Professor Matthias Schwannauer, Head of the School of Health in Social Sciences ([headofschool.health@ed.ac.uk](mailto:headofschool.health@ed.ac.uk)) and the college Research Governance Team ([cahss.res.ethics@ed.ac.uk](mailto:cahss.res.ethics@ed.ac.uk)).

#### Contact details

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