



Easier read Participant Information sheet (8-12 year olds)

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 people aged 8-18 years of age. The information you provide in the app will be used for health research. Helping us to understand and improve the influences on your health.

This sheet is to help you decide if you want to take part in our project.

You can speak to your parent(s) or guardian before you decide if you want to take part (they will get their own sheet like this one to read).

What is the project about?

JournHey? is an app for children and young people about health. Using the app will help you, and researchers, find out what helps or stops children and young people from being healthy where they live. The app is focused on your diet, physical activity, sleep and wellbeing.



In the app 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.

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.

Do I have to take part?

No. You do not have to take part. It is up to you. If you choose not to take part that is fine, and you do not have to say why. You can also change your mind at any time and stop taking part.



Nothing bad will happen if you do not take part or decide to stop taking part later.

What happens if I decide to take part?

If you do decide to take part, you will need to start using the JournHey? mobile phone app. To register in the app, you need to provide your name, date of birth, gender, postcode and an email address we can use to contact you. 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). During this process we will ask you to read and complete an Assent Form, to show that you understand the project and are happy to take part. This form also asks to confirm that you understand and agree with us collecting and using your data.

We will also need your parent or guardians' permission for you to use the app. So, 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.

In the app you will find four sections:

1. **Dashboard** (house icon) – This is where you can:
 - Complete a **daily check-in** on your diet, exercise, sleep and wellbeing using four sliders. Move the slider up for healthier and down for less healthy.
 - Answer the **daily question** related to your diet, exercise, sleep or wellbeing. These questions have been used in other research studies so help us compare your answers with other young people.
 - Each day the question will be different.
 - Once a month it will be a series of questions.
 - Once a week you will be asked about what influenced your health that week.
 - See how many points you have collected by completing activities.
 - See how many days in a row you have been using the app, your streak.
 - See how experienced you are with using the app, your level of expertise.
2. **My Health** (heart icon) – This is where you can:
 - Look back and analyse the data you collect using the **daily check-in** sliders.
 - Explore how your diet, exercise, sleep and wellbeing change over time. This might show connections like having a bad day if you haven't slept well.
 - Uncover how the influences you reported impacted on your diet, exercise, sleep and wellbeing.
3. **Topics** (speech bubble icon) – This is where you can:
 - Start discussions about influences on your health with other young people, or join discussions started by other users.
 - No one will use their names on the discussion boards so you cannot be identified. But you can decide to tell the other users your age group, gender, interests or the area you live, if that information is relevant to the topic.
 - Start or sign petitions about influences on your health that lots of users are experiencing. In the petition you explain what the influence is and how it impacts your health. Then you ask for the change that needs to happen.
 - If enough users sign the petition, it can be sent to the people who might be able to make the changes you want.
4. **Profile** (your avatar icon) – This is where you can:
 - Update your profile, for example, changing your postcode if you move house.
 - Change the app permissions. The app will be able to use the step count data collected by your phone. You can also access your gallery to upload photos to topics or petitions, for example if there was something broken in your local park, you could add a picture of it. If you don't want the app to access your step count or gallery, you can switch this off in your profile.
 - Report problems with the app by emailing the team
 - Find information about who was involved in developing the app

Each day we hope you will use the sliders and answer the question we send. When you have time, we hope you will use the discussion board and petitions. We have worked with young people to design the app and make sure it won't take up too much of your time. We would like you to try using the app for 3 months, but you can keep using it for longer, if you like.

To help us understand what you like and dislike about the app, we will send you a feedback survey. This will be emailed to you once a month and should take 5-10 minutes to complete on your phone.

Is there anything unpleasant that could happen if I take part?



If we ask you anything in the app that you are not happy to answer, you do not have to answer. You can just move on to something else in the app.

As you will be interacting with other young people using the app, here are some things you should think about before posting:

- How would I feel if everyone knew the information?
- Is it possible to tell who I am?
- How would I feel if I got this message?

We will check every discussion board posts before they are shared. We will email you with details of support organisations if we spot anything concerning in how you use the app.

Will I get anything for taking part?

We hope you will find the app enjoyable to use as well as interesting. To thank you for trying out the app, we will offer you a £15 shopping voucher. The voucher will be offered after the first month (4 weeks) you have used the app, if you have used it at least once a week.

What information about me or recordings of me will you collect and how will it be stored and looked after?



All the information you provide through the app will be collected by the University of Edinburgh. The data will be securely stored on a university server. Only the project team listed at the top of this document will be able to look at your information. We follow strict rules to make sure the information is kept safe.

Once a month we will take an **ANONYMISED** back up copy of the data. This means that parts of your information will be changed or removed so that no-one can work out that the information is about you. This anonymised data will be used for research. If you collect data in the app for a school project, this will be used to create a summary report for your teacher or school. In this report the data from all the users in your school or class will be combined. The researchers will make sure that no one reading the report can identify any one from the data.

Other researchers can apply to analyse the anonymised data, if they have ethical approval.

How will you use my information?

We will use your name and contact details to interact with you about the app. You will be able to see the data you collect using the sliders as well as the discussion boards and petitions.



The information collected in the app will be **ANONYMISED** so that researchers can use it. We will analyse the data to find out what helps or stops children and young people from being healthy where they live. The findings of the research will be published. They will also be explained in the discussion boards in the app. We will not name or identify you in any reports or publications.

When will my information be destroyed?



The contact details and other information and data you provide in the app will be stored as long as you continue to use the app. If you close your account and delete the app, we will destroy

your data. But every month we will take an anonymous copy of the data in the app. This will be stored securely at the university for at least 10 years, and then destroyed.

Who will know that I am taking part?

Only the research team will know you are taking part and we will never identify you in anything we say or write about this project.



Use of your personal information and your rights

The way we look after your information (your 'data') is ruled by UK law. Under UK law, we need to have a good reason (called a 'lawful basis') for handling your information. In this case, the reason is to do research which aims to benefit everyone (this means that it is in the 'public interest'). You have the right to make choices about your information under UK law. For more information on this you can visit <https://data-protection.ed.ac.uk/privacy-notice-research>. If you have any questions, you can email dpo@ed.ac.uk or ask an adult (parent, guardian or teacher) to send an email for you.

You can stop taking part and ask for your contact information and to be removed at any time. However, as the monthly back up of the data are anonymised, we will not be able to delete it as we won't know what information is yours.



If you do want to take part

Before you say yes, think carefully about everything in this sheet and ask questions (if you have any)



What should I do if I have questions or am worried about this project or my information?

First, you should talk to your parent or guardian or to one of the researchers. If you would like to speak to someone who knows the research, but is not involved with the project you can contact Dr Stephen Malden (stephen.malden@ed.ac.uk).

If you do not want to talk to us, then you or your parents can contact the Head of the School of Health and Social Sciences (headofschool.health@ed.ac.uk) and College Research Governance Team (cahss.res.ethics@ed.ac.uk). If you would like, you can ask your parents, guardians or teachers to email for you.

Who to contact?

Researcher	Dr Andrew James Williams, Scottish Collaboration for Public Health Research and Policy, School of Health in Social Sciences, University of Edinburgh EH1 2QL andrew.j.williams@ed.ac.uk	School Ethics contact	Dr Maria Gardani (School Ethics Director) School of Health in Social Sciences, University of Edinburgh EH1 2QL ethics.hiss@ed.ac.uk
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