



Parent Information Sheet

Youth health connections – JournHey? app deployment and testing

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Your child is being invited to take part in research on the influences on the diet, activity, sleep and wellbeing. 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 your child provides within the app will be used for health research. Helping us to understand and improve the influences on young people's health. Before you decide whether to allow your child to take part, it is important you understand why the research is being conducted and what it will involve. Please read this document carefully.

It is really important to us that you understand and agree with how we will use your child's data. Please contact the research team (email at the end of the document) if you or your child 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 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 young people to find the data useful so the following features are part of the app:

- Your child will be able to create graphs of their data over time and compared to the influences they log. This approach is called citizen science, as they will be the scientist analysing their own data.
- Your child will be able to chat with other app users about the influences on your health. When they find other young people experiencing the same influence, they will then get the chance to create a petition asking for changes to be made. This approach is called crowdsourcing as your child 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 your child provides 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 your child will have been removed. As a new app we are also keen to hear what your child thinks about it, so will be sending users a feedback survey. This will help us modify and improve the app.

Why has my child been invited to take part?

Your child has been invited to participate as they have shown an interest in using the JournHey? app. Only young people aged between 8 and 18 years of age who live in the UK are able to use the app and

participate in the project. They may have heard about the app through their school, youth group, friends or family.

Do I have to take part?

No, it is up to you and your child to decide whether they wish to take part. This information sheet has been written to help you decide whether to take part. If you do decide that your child can take part, they 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 or your child's medical care or legal rights.

What does taking part involve?

If you do decide to allow your child to take part, please keep this Information Sheet. You will be asked to complete an Informed Consent Form to show that you understand their rights in relation to the research, and that you are happy for them to participate.

Taking part in the study involves installing the JournHey? app on your child's mobile phone. When they register with the app they will firstly be asked to complete an assent form. Giving their assent shows that they understand their rights in relation to the research, and that they are happy to participate.

They will then be asked to provide their name, date of birth, gender, postcode and an email address we can use to contact them. As their date of birth indicated that we need parent or guardians' permission for them to use the app, we also asked for your name and email address. This is so that we can send you this document and an online consent form for you to complete if you are willing for your child to be part of the research. Only if we receive your consent will the child's account be created for them to use the app. They will also be able to select an avatar to use in the app and list some of their 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 diet, exercise, sleep and wellbeing. Whenever using the app, your child can move each slider up and down depending on whether they feel that recently each of those areas of their life have been more or less healthy.
2. Daily question: Each day your child will get a notification about a new question for them to answer. Like the daily check-in sliders these questions are about their diet, exercise, sleep and wellbeing. They are questions used in other research projects and will help us compare your child's data with other statistics. Most days it will just be a single question that they can answer quickly. Once a week the question will ask about the influences on their health that week. Once a month it will be a longer set of questions.
3. Level, points and streak: For each of the activities your child does in the app they will collect points. We will also let them know their streak of using the app every day. They will also move up levels of expertise as they use the app.
4. Viewing your health data: In this part of the app, your child will be able to use graphs to look back over the history of their daily check-in responses. They can use this to see how things are changing over time and how their diet, exercise, sleep and wellbeing might be related to each other. They will also be able to compare their data with the influences they have experienced, to see what impact they have had.
5. Topics: This is the discussion board part of the app. Here your child can start discussions about the influences they have found that made their diet, exercise, sleep and wellbeing better or worse. They will need to decide whether the discussion relates to: time, physical spaces, headspaces, other people, costs or other. When they post a discussion both them and anyone responding will not be

identifiable, but they can choose whether to list their gender, age group, approximate location or an interest to help other users understand the post. Your child will be able to follow and respond to the posts made by others. As your child will be writing and responding to other young people they will need to think about how they might react. Making sure they don't share anything they 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, your child 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 young people's health and they will be asked to say who needs to make the change you want (e.g., their head teacher, a politician, etc.). This will be an anonymous process, but the person receiving the petition will see the names, ages and approximate locations of the signatories.
7. Profile: This is where your child can update their profile information and change their avatar. If they give permission for the app to collect data on their exercise levels automatically from the phone, or to access the photos on their phone then this can be turned off from your profile screen. If they have any problems with the app these can be reported using an email address on their profile screen.

We hope your child will complete the check in and questions daily as well as reviewing or commenting on topics when they have time. We have worked with young people in schools and youth groups to design the app so it will not take up much of your child's time. All the other users of the app are young people like your child (aged 8 to 18 years). We would like your child to use the app for 3 months, but they can continue to use the app for as long as they want, or stop using it early. Once a month we will email your child a short feedback survey so they can give us their opinion on the app and any suggestions they have, this will take 5-10 minutes to complete. We will link their survey responses to the information they have given us on their 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 your child learn about their health habits. It also gives them the opportunity to work with other young people to identify and take action on those things that influence their health. We also hope they 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, at the end of their first month (4 weeks) of use we will offer them a £15 shopping voucher if they have used the app at least once a week.

Are there any risks associated with taking part?

Within the app your child will be collecting data on their 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 users from doing this. When the researchers analyse the data, we will make sure that none of the people providing data can be identified. Your child will also be chatting with other users about the influences on their health, and there are risks related to this. As your child will be writing their own comments they will want to make sure people cannot tell who they are from their 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 your child 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 child's 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 child's 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 your child?

This information will include your name and email address alongside your child's:

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

We will need to use this information to help administer the app and for research. People who do not need to know who your child is will not be able to see their name or contact details. Your child's 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 your child to suggest ways that your approximate location could be identified in the app, and they can select the one they prefer. They can then use this if they are starting a topic about an influence only relevant to people who live near you. We will keep all information about your child safe and secure.

Your child's 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 your child 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 child's responses in order to minimise risk. If your child collects data in the app for a school project, this will be used to create an anonymised report for their 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 child's information is used?

- Your child can stop being part of the study at any time, without giving a reason. To do this they need to close their account in the app and uninstall it. This will delete any not yet anonymised data they have submitted through the app, but their 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 child's anonymised data, if you leave the study.
- We will contact you annually to check that you and your child continue to consent to being part of the project. If you stop consenting to be part of the project your child's account will be closed and their identifiable data will be deleted, apart from petition signatures.

- We need to manage your child's records in specific ways for the research to be reliable. This means that we won't be able to let you or your child see or change the data we hold about your child.

Where can you find out more about how your child's 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

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from your child 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 and your child for as long as they remain a user of the app and provide consent. But this data would be deleted as soon as they close their account and stop using the app. We will keep your child's anonymised data for a minimum of 10 years.

How will my child's 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 your child from the data. With your consent, your child's 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 term listed on the first page of this document 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).

If you would like to discuss this study with someone independent of the study, please contact Dr Stephen Malden (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) and the college Research Governance Team (cahss.res.ethics@ed.ac.uk).

Contact details

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