

## Participant Information Sheet for 11-17 Year Olds- Interviews



**Lead researcher:** Dr Anna Selby

**Ethics/IRAS number:** 332076

### Prescription Alerts for Reliever Inhalers in Children (PARC) Project

Thank you for taking part in the PARC Project. You are now being invited to have a chat with a member of the research team to find out what you thought of the asthma check-up. To help you decide whether you would like to take part or not, it is important that you understand why we would like to talk to you and what this will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information. You may like to discuss it with family or friends, but it is up to you to decide whether you take part.

#### What is the interview about?

We would like to find out what you thought about the asthma check-up you had recently as part of the PARC project. We would like to know what was good about it and whether you think we should do anything differently. Your thoughts and ideas will help us to improve asthma check-ups for children in future.

#### What will the interview involve?

The project team will get in touch with you/a parent or carer to arrange a good time for us to have a chat with you about your experiences. If you decide to take part, you can choose to have the chat via video call, on the phone or in person. It will be led by a member of the project team with training in doing interviews. We would prefer to speak to you alone but if you would prefer to have a parent/carer with you, that is fine. The chat will last about half an hour, and no longer than one hour depending on how much you have to tell us. If you are happy, we will record our chat with you (audio and video) and write it up. You may turn your camera off if you wish. The recording will be stored securely and deleted as soon as it has been written up. It will be anonymised once it has been written up.

#### Are there any benefits in my taking part?

Being involved in research can be a rewarding experience. By sharing your thoughts and ideas about the check-up you had as part of the PARC project, you will have the chance to influence how asthma check-ups for children and young people are carried out in future. This will help to improve the care of children and young people with asthma. You will receive a £10 voucher to thank you for taking part.

## Are there any disadvantages to me taking part?

You will need to give up some of your time. It is important to remember that you can change your mind about taking part at any time. If you have a face-to-face interview, your parent/carer will be given money to cover any travel costs.

## What data will be collected?

Your name and contact details e.g. phone number will be collected. Personal data including your gender and ethnicity will also be collected. This information will help us to make sure that we talk to a wide range of people. Your personal data and typed up interview will be stored separately and will be linked only by your project ID number. This means that when we store your typed up interview, nobody will know that it is your interview.

## Who will know I am taking part?

Taking part and the information you tell us during your chat will be kept private. Sometimes, trusted individuals will ask to look at the information we have collected to check we are carrying out the project correctly. These people have a duty to keep information about you private.

## Do I have to take part and what happens if I change my mind?

It is entirely up to you whether you take part or not. You can change your mind at any time and do not need to give a reason. This will not affect any current or future care you receive.

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

The findings from this project will be used to help decide whether reliever inhaler alerts should be used by doctors and nurses looking after children with asthma. They will also help to make sure that asthma check-ups are done in a way that young people find helpful. No information that could identify you will be shared with other people.

## Who is organising and funding the project?

The project is being paid for by the National Institute for Health and Care Research (NIHR) and is being organised by University Hospitals Southampton NHS Foundation Trust (UHS).

## Who has reviewed the project?

Before any research goes ahead, it has to be checked by a group of people called a Research Ethics Committee (REC) to make sure the research is worthwhile, safe and fair. This project has been reviewed by the West of Scotland Research Ethics Service.

## Contact Details

If you have any questions about this project/would like more information, please contact a member of the research team (led by Dr Anna Selby and Professor Graham Roberts).

Email: [parc@uhs.nhs.uk](mailto:parc@uhs.nhs.uk)

Phone: 07584 613936



Thank you for reading this information sheet.

### Data Protection Privacy Notice

#### How will the research team use information about me?

We will need to use information that you and your GP have given us about you for this research project.

This information will include:

- Your name
- Your age
- Your gender
- Your ethnicity
- Your contact details

This information will be held securely at the University Hospitals Southampton NHS Foundation Trust (UHS)/University of Southampton. It will be used 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 project ID number. We will keep all information about you safe and secure. Once we have finished the project, 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 project.

#### Where can I find out more about how my information will be 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/) and [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- By contacting the research team (details above)
- By contacting UHS's Data Protection Officer ([dataprotection@uhs.nhs.uk](mailto:dataprotection@uhs.nhs.uk))

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

You can stop being part of the project at any time, without giving a reason. 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.

For the purposes of data protection law, the University Hospitals Southampton NHS Foundation Trust (UHS) is the 'Data Controller' for this project, which means that UHS is responsible for looking after your information and using it properly. UHS will keep identifiable information about you for up to 15 years after the project has finished. After this, any link between you and your information will be removed. To safeguard your rights, we will use the minimum personal data necessary to achieve our research project objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. UHS will not do anything with your personal data that you would not reasonably expect.